
Nebraska Child Death Review Report For 2002 - 2003

The fourth report of the
Nebraska Child Death Review Team
July, 2006

July, 2006

The Honorable Dave Heineman, Governor
Honorable Members of the Nebraska State Legislature

I am submitting this fourth report of child deaths in Nebraska, in accordance with Nebraska Revised Statute §71-3404. The report encompasses the Child Death Review Team's findings on the 575 deaths that occurred to Nebraska resident infants and children during 2002 and 2003, and also highlights trends from 1996 to 2003. Given the Team's limited resources and the desire for timely but accurate data, we anticipate best meeting the statutory requirement for yearly reports by reporting on 2004 and 2005 deaths by the end of this year.

While the overall number of child deaths has declined over the past decade, it is clear from our reviews that many of these deaths should not have occurred. During 2002 and 2003, too many children died in automobile crashes, suffered violent, abusive or neglectful deaths, or took their own lives. Furthermore, children continue to die from preventable birth defects and from treatable medical conditions such as asthma.

Finally, the disparities persisting among our state's different racial and ethnic groups indicate that improvements related to health care and education have not reached all families. The report presents recommendations that set out actions for policy makers, physicians, health care providers, communities, parents and others to take that can bring the number of unnecessary deaths down even further. We also provide updates on recommendations from previous reports.

Please note that the views and recommendations of this report are those of the Child Death Review Team, and are not necessarily those of the Nebraska Health & Human Services System.

On a personal note, chairing the Child Death Review Team over the past five years has been an extremely rewarding experience. However, my current duties as Chief Medical Officer for the State preclude my being able to continue in this position. Dr. Dan Noble, Deputy Chief Medical Officer, will assume the Chair position effective July 1, 2006. Other current CDRT members are listed in the beginning of the report.

If I can be of any further assistance, please do not hesitate to contact me. We thank you for your support of the children and families of Nebraska.

Sincerely,

A handwritten signature in dark ink, appearing to read 'Joann Schaefer', with a stylized, flowing script.

Joann Schaefer, M.D., Chief Medical Officer
Chair, Nebraska Child Death Review Team
Director, Department of Health & Human Services Regulation & Licensure
Nebraska Health and Human Services System

The Child Death Review Team would like to thank the County Attorneys and their staff, hospital Medical Records Departments, Tribal Authorities, State agencies, HHSS staff, family members and other individuals who graciously provided the information that made this report possible.

This report was designed to provide useful information for evaluation, planning and prevention purposes. Any questions or comments regarding the report or the Nebraska Child Death Review Team should be directed to:

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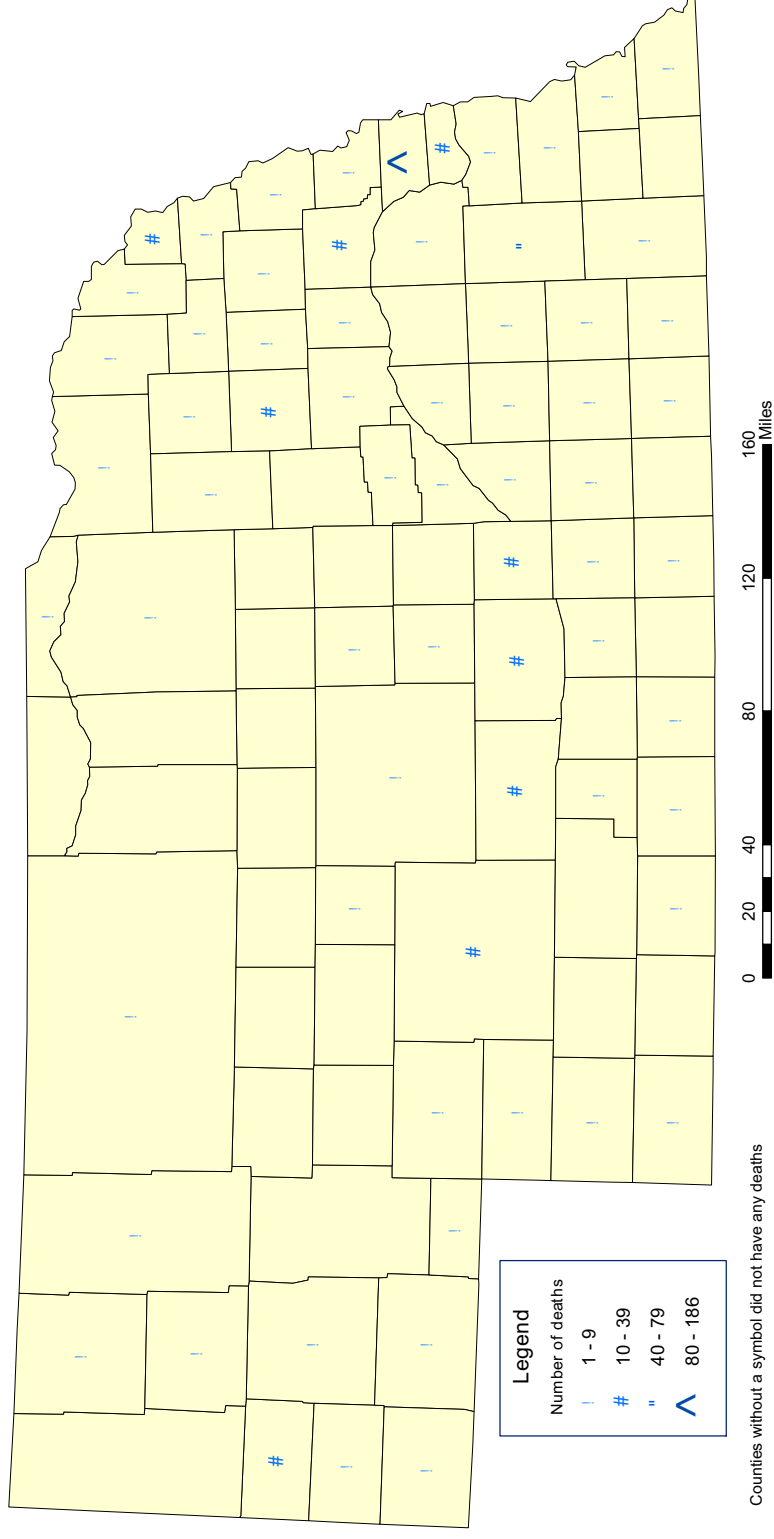
This report is also available at www.hhs.state.ne.us/srd/srdindex.htm and <http://www.hhs.state.ne.us/hew/fah/CDRteam/reports.htm>.

Members of the Nebraska Child Death Review Team, 2002 - 2006

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Infant and Child Deaths (0-17) by County of Residence (N=575) Nebraska, 2002-2003



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Executive Summary

The Nebraska Child Death Review Team (CDRT) was established by the Nebraska Legislature in 1993 and charged with undertaking an ongoing, comprehensive review of existing information regarding child deaths in Nebraska. This report presents the CDRT's findings and recommendations based on review and analysis of deaths of the 575 Nebraska resident children (newborns through 17 years of age) who died during 2002 and 2003.

The overall death rate of children in Nebraska has gone down by 26%, from 361 deaths (82.6 /100,000 children 0-17) in 1993 when child death reviews began to 267 deaths (61.0 /100,000) in 2003. Overall death rates for African-American, Native American and Hispanic children were higher than for White and Asian children, a pattern observed during the previous review period (1996-2001). Further analyses of the records are needed to understand specific causes of death that contributed to these overall mortality disparities.

Top Ten Causes of Death for Children in Nebraska, 2002-2003, and Key Recommendations for Future Prevention

1. Pregnancy-Related – 145 deaths

Pregnancy-related factors such as prematurity, maternal complications, and events of labor and delivery were the underlying cause of 25% of all infant and child deaths during 2002 and 2003. However, the underlying cause of death for most premature infants was not their prematurity – two-thirds (66.7%) had either a known reason such as maternal pre-eclampsia for the prematurity, or a distinct cause of death other than their immature development. Among the infant deaths that were attributed to prematurity, close to half (45.6%) were to multiple gestation infants who are known to have both higher prematurity and mortality rates. Preconception care – biomedical and behavioral interventions implemented before the start of pregnancy, may represent the best opportunity to reduce perinatal risk factors and improve pregnancy outcomes.

- ***Preconception care should be considered a vital and routine aspect of care for all reproductive age women.***
- ***All pregnant women should have access, including financial, linguistic and cultural access, to high quality prenatal care.***
- ***Providers who care for pregnant women should understand the extent to which maternal complications of pregnancy such as placental abruption contribute to prematurity, infant mortality and maternal morbidity, and be aware of current prevention and/or medical management recommendations.***

2. Birth Defects, Inherited and Chromosomal Disorders – 129 deaths

Heart defects were the largest category of lethal birth defects, and hypoplastic left heart disease was the single most common diagnosis. The causes of most birth defects, including chromosomal anomalies, are unknown. However, women who do not take multi-vitamins, who use alcohol, tobacco or other drugs, who are overweight or who have diabetes are at higher risk of having a child with birth defects.

- ***Women of childbearing age, whether or not they plan on becoming pregnant, should consume a daily multi-vitamin containing 400 micrograms of folic acid.***

3. Motor Vehicle-Related Incidents – 92 deaths

Eighty-four percent (83.7%) of motor vehicle-related deaths occurred to children killed while riding in a motor vehicle, including two children in all terrain-type vehicles (ATV) crashes. While the total number of children killed in motor vehicle-related incidents has declined over time, under-use of age-appropriate restraints (safety belt or child safety seat) continues to be a major factor. Statewide, alcohol was involved in one out of five crashes where a child died.

- ***Nebraska's safety belt law should be upgraded to primary (standard) enforcement.***
- ***Parents should limit the number of teenage passengers a teen driver may carry.***
- ***Better enforcement of the state law against serving alcohol to intoxicated bar and restaurant patrons would likely reduce alcohol-related crash fatalities by approximately 11%.***
- ***Parents should be aware of the high potential for serious injury and even death when ATVs are ridden or operated by children under 16.***

4. Infectious, Chronic and Other Medical Conditions – 44 deaths

"Other" medical cases include a wide mix of preventable and non-preventable conditions. Because many of the medical records and/or death certificates merely listed the cause of death as "pneumonia" without specifying a specific causal agent, it was not possible to quantify the number of fatal influenza cases among the 10 known pneumonia and bronchitis-related deaths. Two deaths were reported from asthma, one to a child regularly using an inhaler and the other to a child with unrecognized asthma.

- ***Children with persistent asthma should be taking a daily prevention medicine, the most effective being inhaled corticosteroids. Reliance on albuterol-based inhalers in an emergency should not be considered effective control of asthma.***
- ***Annual influenza vaccine is now recommended for healthy children ages 6 to 23 months, and for older children with specific health conditions.***

5. Sudden Infant Death Syndrome (SIDS) - 42 deaths

The number of SIDS deaths in Nebraska has dropped by one-half since the early 1990s but the trend appears to have leveled off, particularly among African-American infants. At the same time, concerns have been raised that cases of unintentional suffocation, metabolic disorders, other known medical causes of sudden death and even homicide may be misdiagnosed as SIDS. As a result, in addition to 42 deaths officially diagnosed as SIDS, the Team reviewed an additional 10 sleep-related infant deaths. Of these 52 cases, 50 (96.2%) had at least one of six major risk factors for a sleep-associated death. Fifteen percent of the deaths were known to have occurred while the child was in a child care setting (licensed or unlicensed) or with a non-family member babysitter.

- ***Infants should be placed wholly on their back for every sleep.***
- ***Regulations for infants in licensed child care facilities should be revised to mandate back sleeping, recognizing the need for a waiver in some situations, and to repeal requirements for "bumper pad" and stuffed toys in cribs.***
- ***Smoking during and after pregnancy is a risk factor for multiple infant illnesses and state-supported efforts to reduce prenatal and postpartum smoking should be supported and expanded.***
- ***A standardized death scene investigation should be conducted for all unexpected child deaths. Doll reenactments should be part of the investigative protocol for sleep-related infant deaths.***
- ***Existing SIDS prevention regulations, messages and initiatives should be expanded to include other "Safe Sleeping" issues and options, and continue to be widely promoted.***

6. Unintentional Injuries – 32 deaths

The majority of unintentional injury deaths were from drowning (21.9%), being hit by a vehicle not in traffic (e.g., driveways; 15.6%), residential fire (12.5%), and accidental suffocation or hanging (12.5%). One child was killed while playing with a firearm.

- ***Young children should never be unsupervised in or near water, even shallow wading pools.***
- ***Young teens should not be left alone in potentially hazardous situations such as when swimming in lakes and rivers. The ability to swim does not replace the need for supervision, even into the teenage years.***
- ***Children who are in the vicinity of moving motor vehicles or machinery should be under focused adult supervision at all times.***
- ***Parents who keep firearms in the home must understand the importance of storing unloaded firearms and ammunition in separate, locked and inaccessible locations.***

7. Homicide / Criminal Child Abuse & Neglect – 28 deaths

Twenty-eight children suffered violent, abusive or neglectful deaths during 2002 and 2003; children under five and older teenagers were at highest risk. Eight children between the ages of 12 and 17 were shot, stabbed or strangled in disputes with friends or peers; the manner of death in one case of peer assault is unknown. Of the 19 younger children killed by adults, causes of death include blunt force trauma (e.g., having their head hit against a hard surface), chronic physical abuse, Shaken Baby / Shaken Infant Syndrome, being forcibly held in scalding water, and being caught in adult gun violence.

- ***Schools, communities and others concerned about youth violence should be aware of and take advantage of the substantial resources available to help develop effective, community-based prevention programs.***
- ***Statewide, voluntary home visiting programs are needed that provide support and assistance to expecting and new mothers in their homes.***
- ***Never leave a child in the care of someone who is abusing drugs, especially methamphetamines.***
- ***“Never, never, never shake a child” is an excellent starting point for developing community norms against child abuse.***
- ***Relatives, friends and neighbors should follow their instincts – and the law - when they suspect substance abuse, child abuse and/or neglect by the caretakers of young children.***

8. Suicide – 22 deaths

During 2002 and 2003, at least 22 children ranging in age from 11 to 17 and living in 14 Nebraska counties took their own lives. Cases reviewed by the Team tended to fall into three groups - youth with identified mental health issues where the suicide was not a complete surprise; youth with no identified mental health issues but who tended to have trouble in school, didn't fit in well, and/or didn't feel much hope; and purely situational cases.

- ***All teenagers need access, including financial access, to confidential, professional mental health services.***
- ***Any suicidal gesture, no matter how “harmless” it seems, demands immediate professional attention.***
- ***Parents who keep firearms in the home must understand the importance of storing unloaded firearms and ammunition in separate, locked and inaccessible locations. Trigger locks are an important component of firearm safety.***

9. Cancer – 21 deaths

The number of child cancer deaths continued to drop during 2002 and 2003, but cancer remained the most common cause of disease-related mortality. Leukemia and brain tumors were the most common causes of child cancer deaths in Nebraska as well as nationally. The cause of most childhood cancers is unknown.

- ***Providers should stay up to date on findings regarding risk factors for, causes of and treatments for childhood cancers.***

10. Caretaker Neglect – 7 deaths

There were seven cases where the local county attorney chose not to prosecute, but CDRT reviewers felt that the death would not have occurred under reasonable standards of supervision or care. Five of these cases involved children under five drowning in a bathtub, container or swimming pool, one child was attacked by the family dog, and one child became wedged under a reclining chair and suffocated. Two additional cases were left as “Inconclusive,” where reviewers were not comfortable with the unintentional injury classification but did not have sufficient information to clearly determine or rule out neglect.

- ***Young children should never be left unsupervised.***
- ***Safe and affordable child care will reduce the number of children left unattended for long periods of time.***

B ackground

Review of 2002-2003 Nebraska Child Deaths

The Legislature finds and declares that it is in the best interests of the state, its citizens and especially the children of this state that the number and causes of death of children in this state be examined. There is a need for a comprehensive integrated review of all child deaths in Nebraska and a system for statewide retrospective review of existing records relating to each child death. §71-3404 Neb. Rev. Stat.

This report presents the findings and recommendations of the Nebraska Child Death Review Team, based on the review and tabulation of the 575 deaths of Nebraska resident children (newborns through age 17) known to have occurred during 2002 and 2003. The traditional belief that “things will happen” ignores the reality that many of these deaths could have been prevented.

BACKGROUND

The Nebraska Child Death Review Team (CDRT) was established by the Nebraska Legislature in 1993 and charged with undertaking a comprehensive, integrated review of existing records and other information regarding each child death. At that time, the Nebraska Commission for the Protection of Children had found that about 300 children died each year in the state, but that there was no systematic process in place for consistent review of those deaths to determine contributing circumstances.

The purpose of the CDRT includes developing an understanding of the number and causes of child deaths, and advising the Governor, Legislature, other policy makers and the public on changes that might prevent them in the future. All child deaths are reviewed, not just “suspicious” or violent ones. The Team uses information in written records and the expertise of its members to identify situations where, in retrospect, reasonable intervention might have prevented a death. Members of the original Team determined that the specific goals of these reviews would be to:

- Identify patterns of preventable child deaths;
- Recommend changes in system responses to child deaths;
- Refer to law enforcement newly-suspected cases of abuse, malpractice, or homicide; and,
- Compile findings into reports designed to educate the public and state policy makers about child deaths.

Three previous reports have been issued, covering child deaths in 1993, 1994/1995, and 1996-2001.

Methadology

In making its assessments, the Team obtains information from multiple sources, including:

- The Vital Records section of the Nebraska Health and Human Services System (HHSS), which provides death certificates for all Nebraska resident children under the age of 18, and matched birth certificates for those under the age of one year;
- County Attorneys, who are contacted annually for information on all deaths to children who resided in their respective counties;
- Hospitals, which are contacted annually for information on all deaths to children that occurred in those facilities;
- The HHSS Office of Protection and Safety and the Child Care Licensing section;
- Additional sources as needed, e.g., private providers, public officials in counties or states where a death occurred but where the child was not a resident.

The annual State of Nebraska Vital Statistics Reports provide categorized cause of death information for infants and older children. However, the CDRT review determines underlying causes that do not always correspond to those assigned by Vital Statistics, as the Team tends to reach further back in the chain of events that led to the death to assign a cause.¹ As the goal of the CDRT is prevention of future deaths, this process was felt to better distinguish between preventable and non-preventable deaths.

The Team also uses HHSS electronic databases, including children's birth and death certificates. Numbers and names of Sudden Infant Death Syndrome (SIDS), suicide, homicide and criminal child abuse cases were compared to ensure that all children known to the state were listed appropriately in the CDRT files. Similarly, the state's Cancer Registry is used to cross-check cancer deaths. The Nebraska Crash Outcome Data Evaluation System (CODES) database provides aggregate data on passenger restraint (e.g., seatbelt) use and the involvement of alcohol in automobile crashes. CODES data were not individually matched to CDRT cases but do provide an aggregate assessment of the same children and incidents. Finally, in a small number of cases, the only information available was obtained from archived newspaper reports.

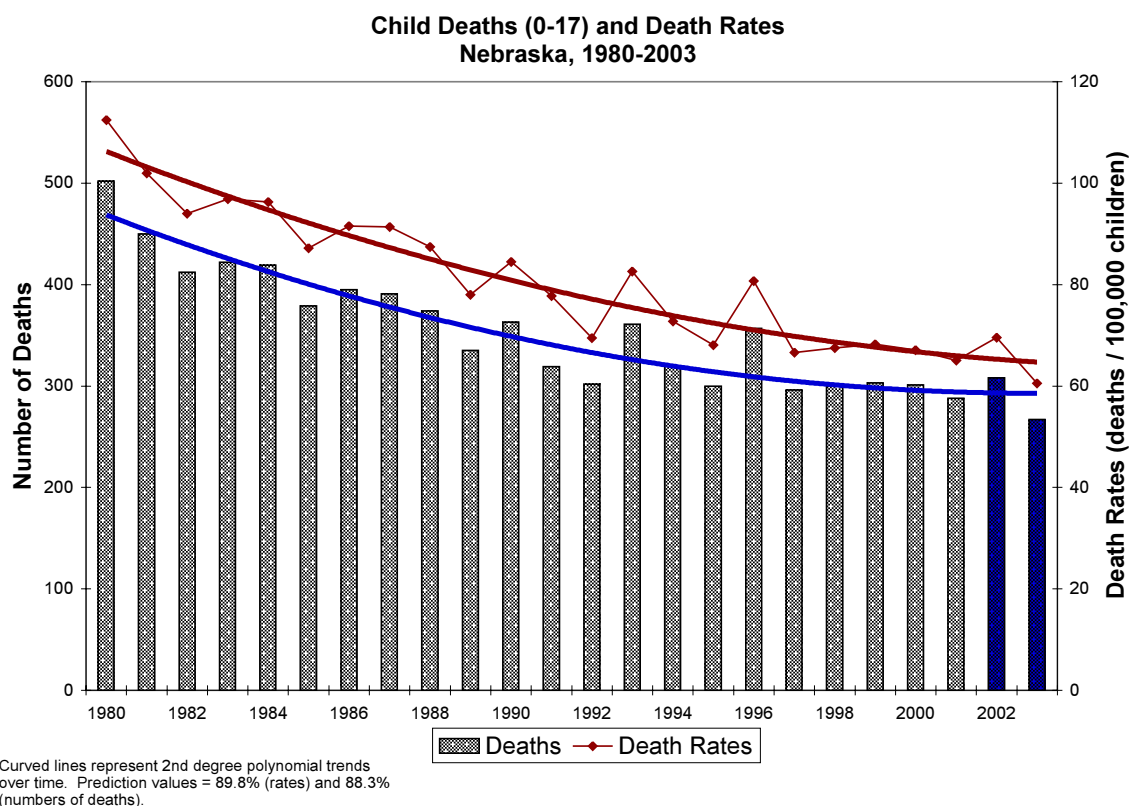
Using this information, the CDRT Coordinator reviewed all cases and classified them into one of 16 categories based on the underlying cause and circumstances of death. Because information was incomplete for some children, some misclassification may have occurred. Team members discussed cases where the classification was not immediately obvious or was controversial. Most cases were not individually assessed for preventability; however, all unintentional injuries ("accidents") to young children, child abuse cases and suicides were reviewed by at least two Team members to determine whether caretaker neglect may have been involved.

¹ The underlying cause of death is the disease or condition that initiated the chain of morbid events leading directly to death, and may be many years removed from the actual occurrence of death. See Glossary for further discussion.

Findings

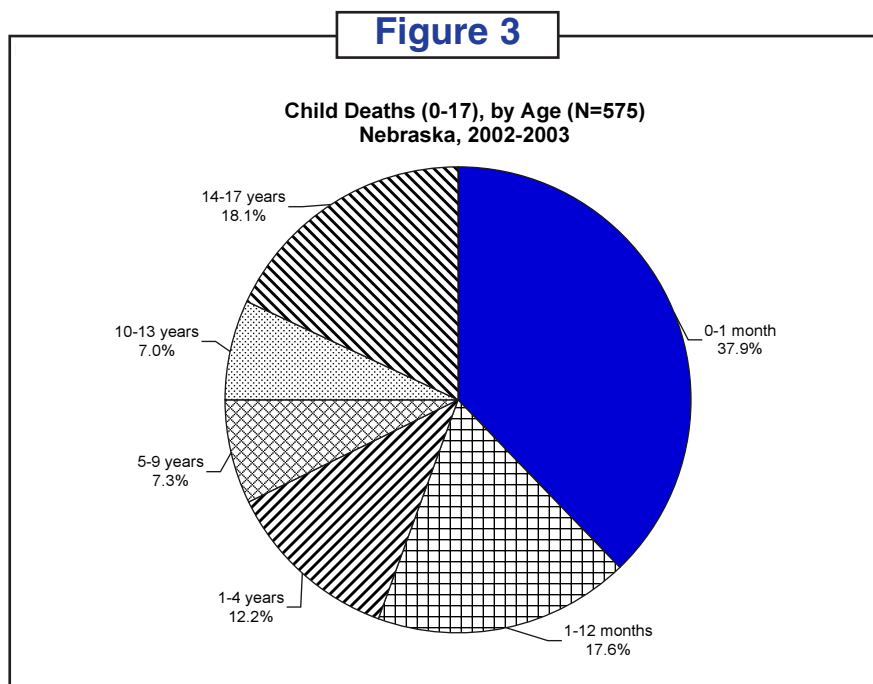
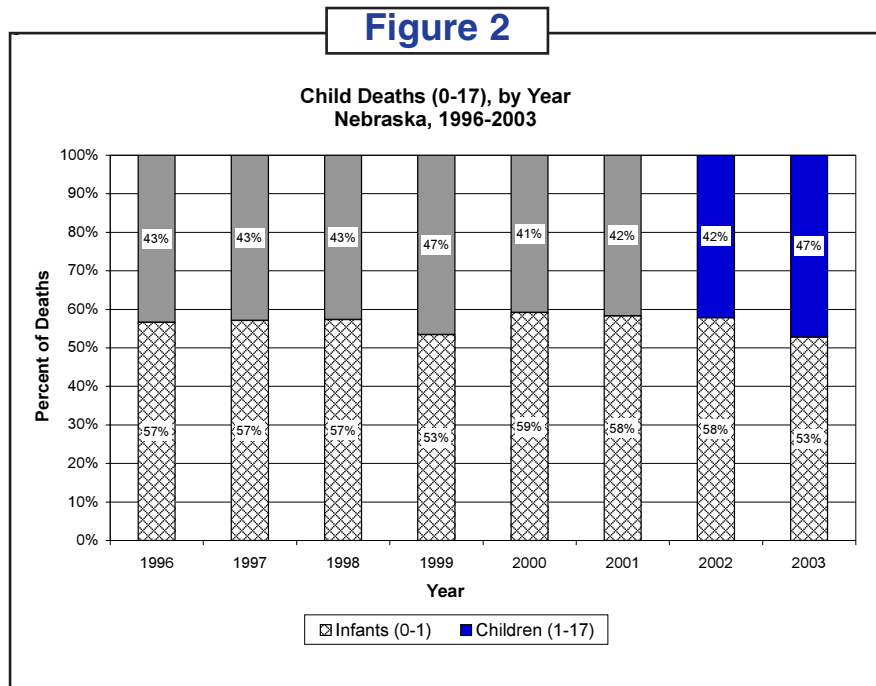
A total of 575 Nebraska children ages 0 to 17 died during 2002 and 2003 (Table 1). This represents a 26% decrease in the number of deaths since when child death reviews began (from 361 deaths in 1993 to 267 deaths in 2003), and a 26% decrease in the death rate (from 82.6 deaths per 100,000 children 0-17 to 61.0 deaths per 100,000). It is also a hopeful indication that the 20-year trend of decreasing deaths may be resuming, compared to the relative plateau observed during the 1996-2001 period (Figure 1).

Figure 1



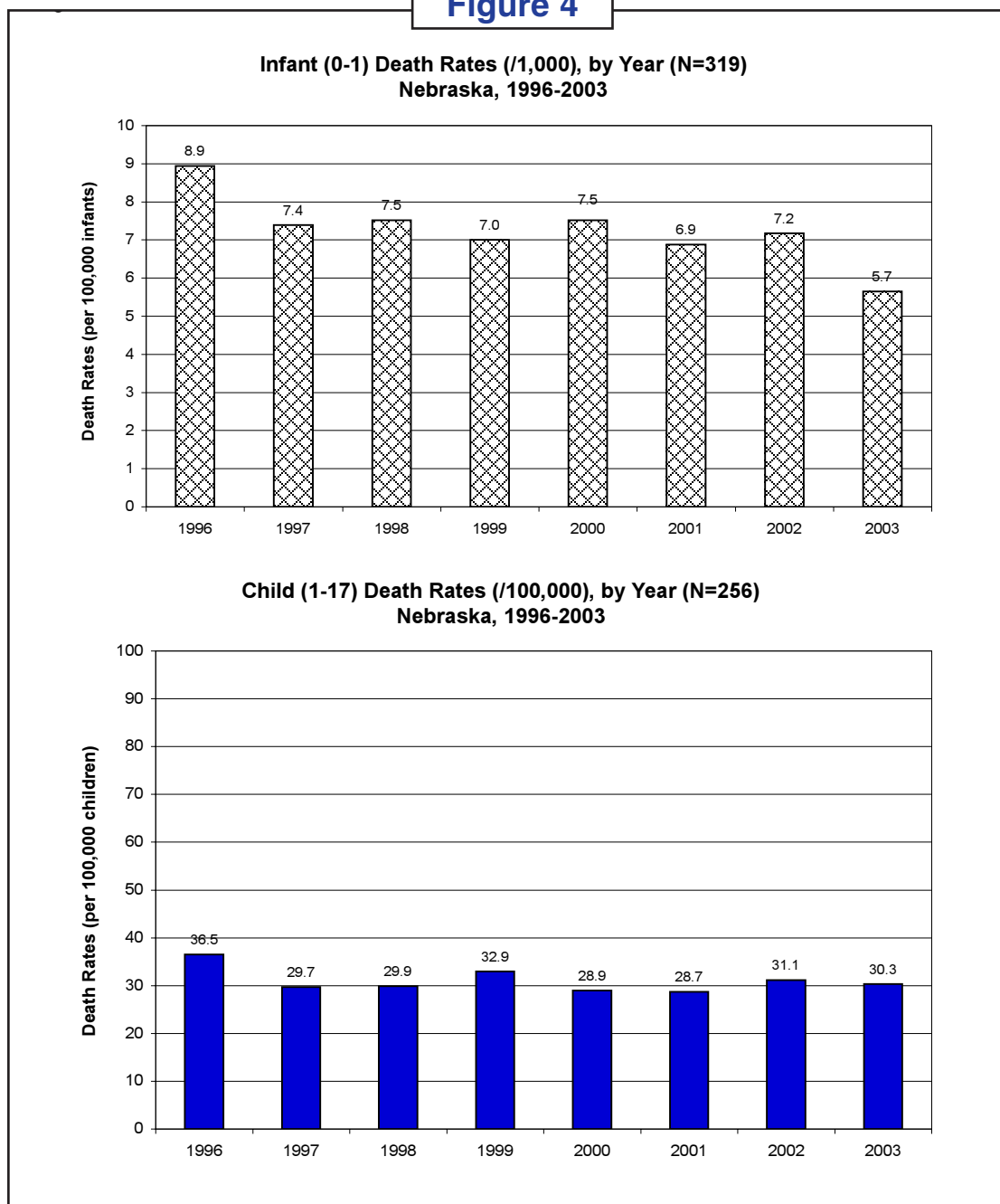
Demographics

Infants less than 12 months old accounted for approximately 56% of all deaths, consistent with previous years (Figure 2). Of these, about two-thirds died in their first month (Figure 3). Overall, the infant death rate, though not the child death rate, declined slightly during 2002 and 2003 (Figure 4).



The children were predominantly male (57.7%) and White (83.1%) (Figure 5). African-American children made up 12.7% of deaths, Native American 2.8%, Asian 0.3% and Hispanic² children 11.5%. When calculated as a rate per 100,000 children, African-American, Native American and to a lesser extent Hispanic children had significantly higher death rates than did White and Asian children (Figure 6). All groups showed evidence of declining mortality over time (Figure 7).

Figure 4



² Persons of Hispanic origin may be of any race, thus race and ethnicity percentages sum to greater than 100 percent.

Figure 5

**Distribution of Child Deaths (0-17),
by Sex, Race and Ethnicity (N=575)
Nebraska, 2002-2003**

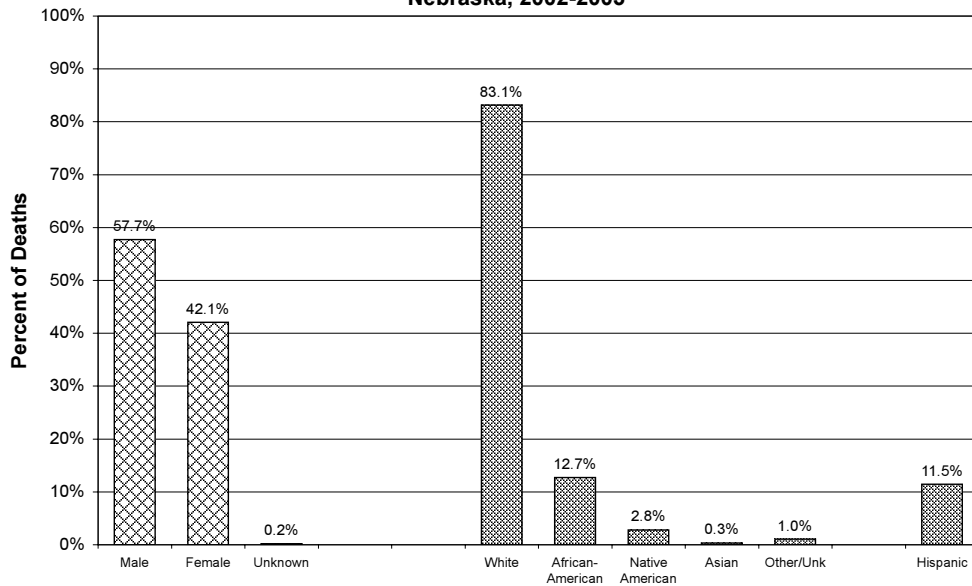
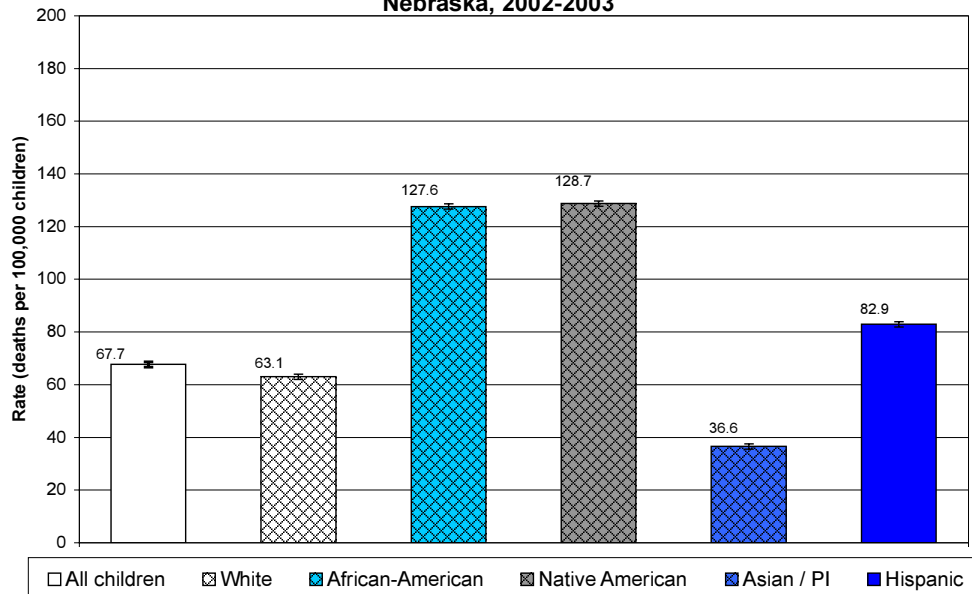


Figure 6

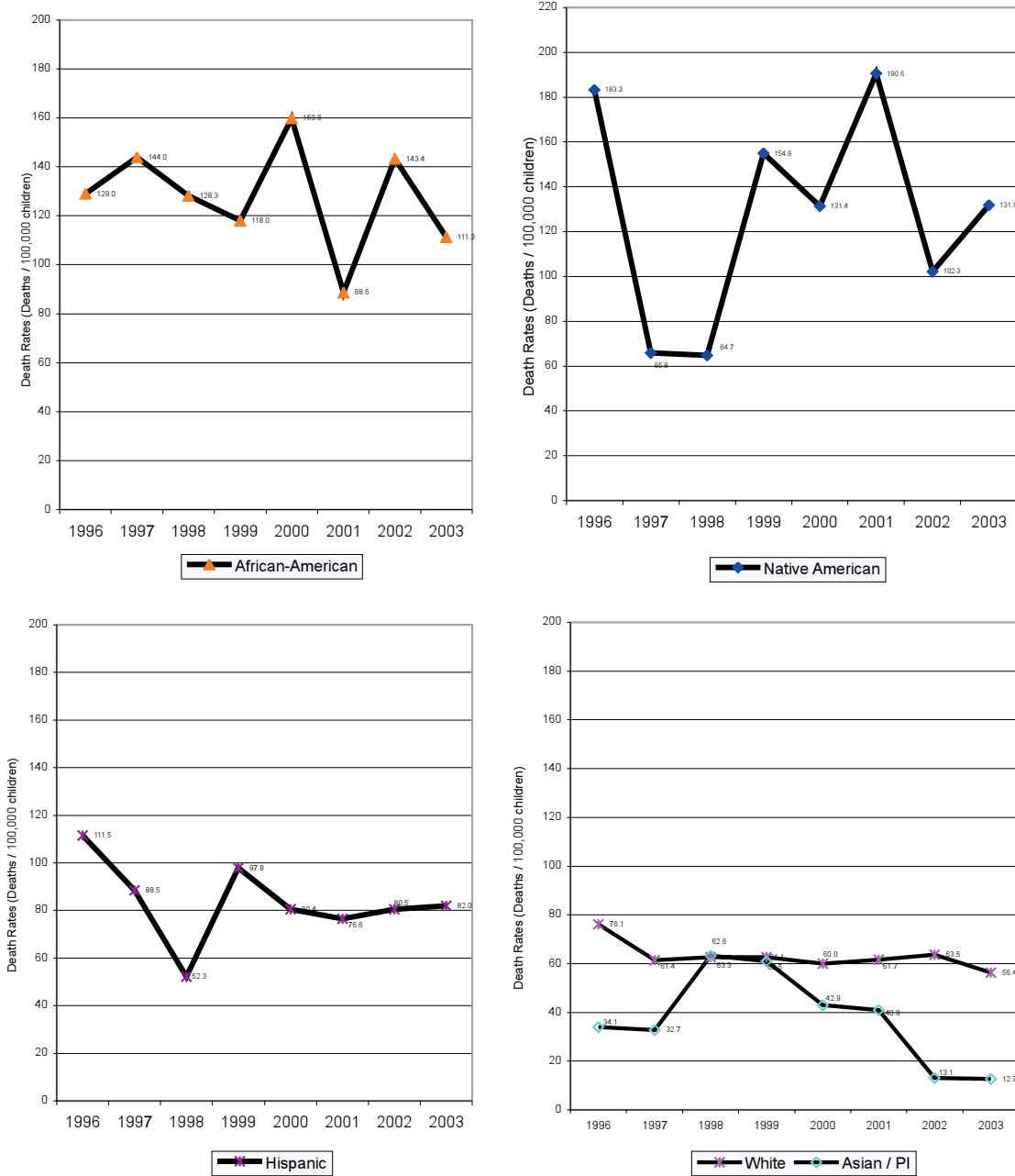
**Child Death Rates (0-17), by Race/Ethnicity (N=569)*
Nebraska, 2002-2003**



Hispanics can be of any race. Six children were of other non-White or unknown race and are not included in these calculations. Thin bars represent 95% confidence intervals.
Source: Centers for Disease Control and Prevention.

Figure 7

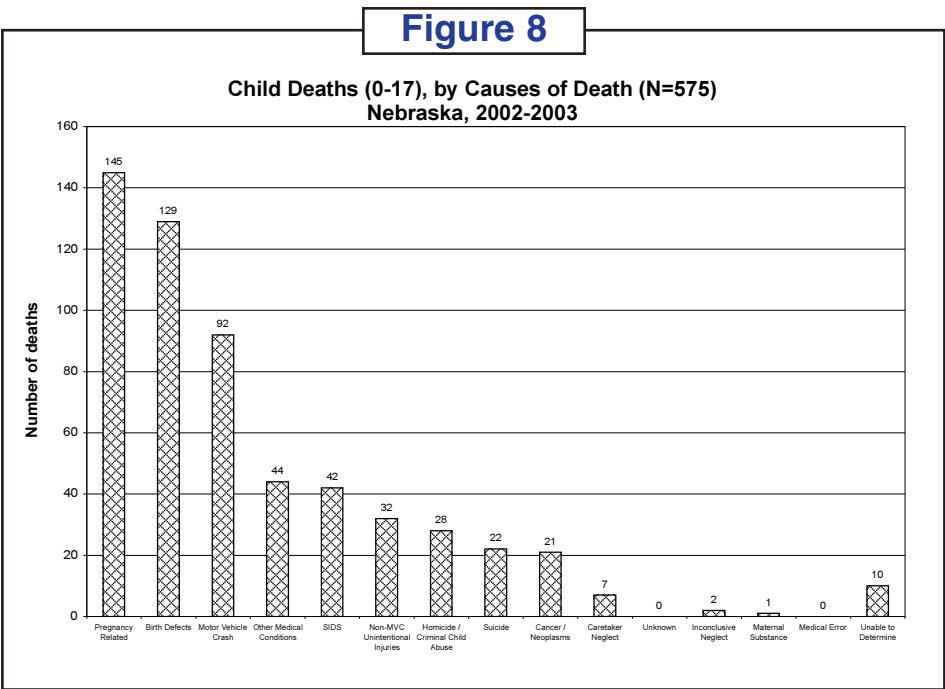
Child Mortality Rates (0-17), by Race / Ethnicity
Nebraska, 1996-2003



Causes of death

Overview

Based on the Team’s reviews, one-quarter of all deaths (25.2%) during the two-year period were attributable to “Pregnancy-Related” causes, a combined category of maternal complications during pregnancy, labor and delivery problems, and prematurity (Table 1; Figure 8). Birth defects were the second most common underlying cause with 22.5% of all deaths; various medical conditions accounted for an additional 18.6% of deaths. One-third (32.1%) of deaths were attributed to non-medical conditions of which the majority were preventable.



Pregnancy-Related Deaths - Key Findings

Factors related to pregnancy accounted for 25.2% of all deaths over the two-year period (Table 1); all but two of these were of infants (less than 12 months old). Prematurity, being born at a gestational age of 37 weeks or less, is widely considered a leading cause of infant death. However, births of at least 28 weeks gestational age are generally considered “viable,” provided that specialized neonatal care is available. Correspondingly, while 204 (63.9%) of the 319 Nebraska infants who died during 2002-2003 were documented as having been born early, prematurity was felt to be the underlying cause of death for only 68 (33.3%). The other 136 infants (66.7%) had either a known reason for their prematurity or a distinct cause of death other than their immature development (Figure 9). Thus, for example, maternal complications were considered to be the underlying cause of death for an infant delivered at 23 weeks of gestation from a pre-eclamptic pregnancy.

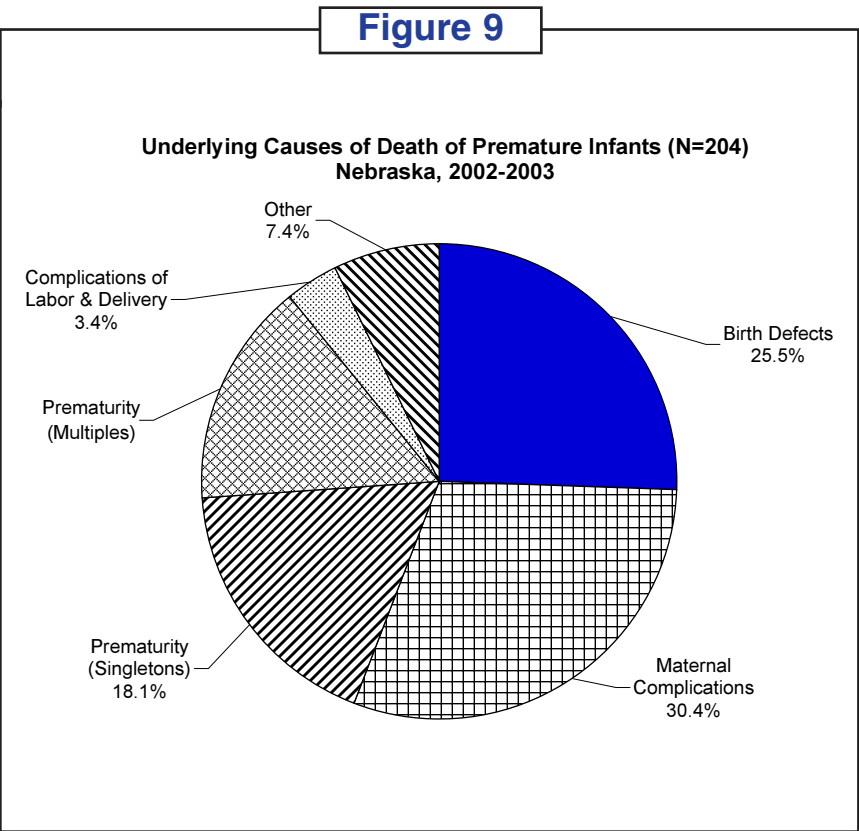
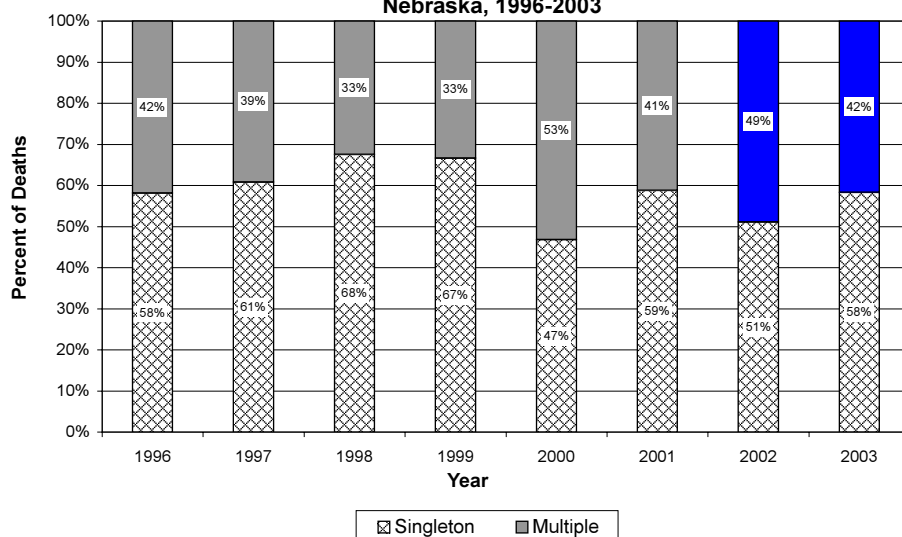


Figure 10

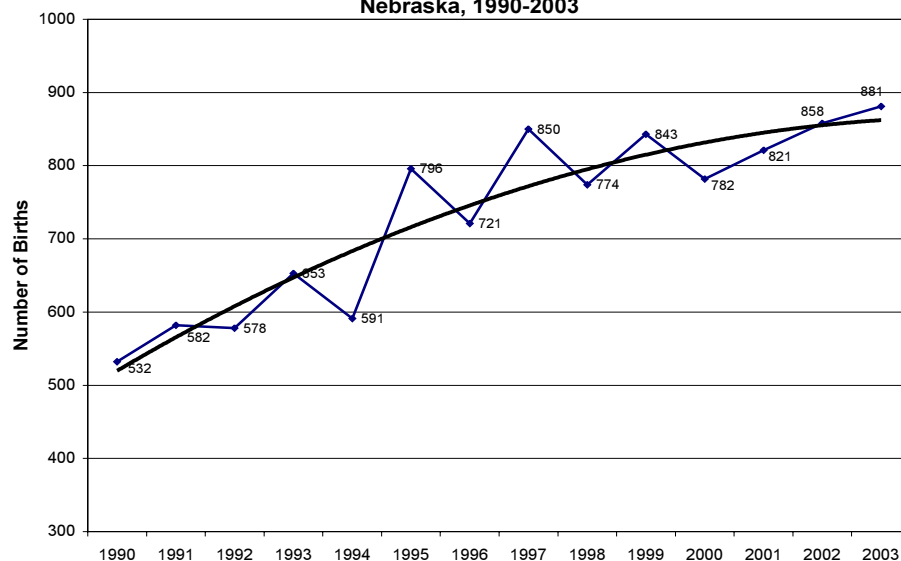
**Infant and Child Deaths (0-17) Attributed to Prematurity,
by Type of Pregnancy
Nebraska, 1996-2003**



The 68 infant deaths that were attributed directly to premature birth were split fairly evenly between multiple³ (45.6%) and single gestation infants (54.4%) (Table 2; Figure 10). Both prematurity and mortality rates for multiple gestation infants are considerably higher than for singletons, resulting in a significant impact of multiple births on Nebraska's prematurity-related death rates. The annual number of multiple births in Nebraska continues to increase (Figure 11).

Figure 11

**Multiple Gestation Births, by Year
Nebraska, 1990-2003**



Source: Nebraska Vital Statistics Report
Curved line represents the 2nd degree polynomial trend over time. Prediction value = 85.7%.

³ Twins, triplets and quadruplets. All multiple gestation infants who died were premature.

A comparable number (69 deaths) of pregnancy-related deaths were attributed to maternal complications, the most frequent of which were incompetent cervix and placental abruption (Table 3). Five percent (eight deaths) of pregnancy-related deaths resulted from complications during labor and delivery, particularly from oxygen deprivation of the fetus during the birth process (Table 4).

Discussion

The prevention of premature birth is the focus of many national and local efforts. Considerable attention is being paid to “pre-conception care,” biomedical and behavioral interventions designed to reduce perinatal risk factors and improve pregnancy outcomes. These interventions must be implemented before the start of pregnancy to have any influence on its outcome, under the belief that a woman’s health status before she becomes pregnant has as much influence on the probability that a pregnancy is carried to term as do events during the actual pregnancy.

At the same time, medical care during pregnancy remains an important determinant of outcomes. The Nebraska Medical Association (NMA) periodically reviews neonatal deaths for the quality of their medical care. Among the conclusions of their review of 118 neonatal deaths (less than 28 days old) between July 2002 and July 2004 were the following:

- The percentage of mothers who had received adequate prenatal care improved from the previous period;
- Maternal chorioamnionitis and placental abruption are significant problems;
- Educational interventions for providers may be needed around appropriate diagnosis and treatment of vaginitis during pregnancy; and,
- The autopsy rate for neonatal deaths has improved but continues to be unsatisfactory; and,
- The availability and appropriateness of translators may be affecting the ability to provide the best care and information to all patients.

The Federal standards for culturally and linguistically appropriate services (CLAS; Federal Register Doc. 00-32685) in health care are not yet widely known or applied across the state. The CLAS standards state that health care organizations receiving federal funds must offer and provide language assistance services, including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency at all points of contact, in a timely manner during all hours of operation. The standards are responding to the need for all people entering the health care system to receive equitable and effective treatment in a culturally and linguistically appropriate manner, and to make services more responsive to the individual needs of all patients/consumers. The standards are intended for use by:

- Providers, to understand and implement services that are accessible to and appropriate for diverse populations;
- Policymakers, to draft consistent and comprehensive laws, regulations, and contract language;
- Patients, to understand their right to receive accessible and appropriate health care services, and to evaluate whether providers can offer them;
- Advocates, to promote quality health care for diverse populations and to assess and monitor care being delivered by providers;
- Educators, to incorporate cultural and linguistic competence into their curricula and to raise awareness about the impact of culture and language on health care delivery;
- The health care community in general, to debate and assess the applicability and adoption of culturally and linguistically appropriate health services into standard health care practice.

➤ **Recommendations**

State Policy Makers: *All pregnant women should have access, including financial access, to high quality prenatal care.* Women who do not receive prenatal care are more likely to have pregnancies and/or newborns that incur larger publicly-paid expenses.

Successful and widespread implementation of CLAS standards requires political will, enforcement, and likely financial assistance to many local providers. Limiting cultural and linguistic access to quality health care affects the health status of the entire community.

Physicians and Other Health Care Providers: *Preconception care should be considered a vital and routine aspect of care for all reproductive age women.*

All personnel who are involved in the care of pregnant women, their fetuses, and their neonates should be aware of the current Guidelines for Perinatal Care of the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists. These Guidelines are a comprehensive resource on the organization and content of perinatal health services.

Providers who care for pregnant women should be aware of new treatments available for the prevention of preterm labor, and the situations for which they are appropriate. Providers who care for pregnant women should understand the extent to which maternal complications of pregnancy such as placental abruption contribute to prematurity, infant mortality and maternal morbidity, and be aware of current prevention and/or medical management recommendations.

Physicians, Coroners and Pathologists: *Continuing education on accurate determination of the cause of death should be provided to all persons who fill out death certificates.* Incorrect or vague causes of death affect the ability to monitor trends and inform prevention and treatment programs.

Health Care Advocates and Families: *All consumers should be aware of their rights to culturally and linguistically appropriate health care under the federal CLAS standards.*

Early and regular prenatal care is one of the best ways to promote a healthy pregnancy. During prenatal care visits, women can discuss with their health care provider warning signs of preterm labor, and receive individualized assessments of other potential complications.

Birth Defects / Congenital Anomalies - Key Findings

Birth defects accounted for one in five of the infant and child deaths (22.4%, or 129 deaths), comprising the second largest cause of death category. Approximately one-third of these deaths occurred within the first day of life (Figure 12). Heart defects were the largest category of lethal defects; hypoplastic left heart disease was the single most common diagnosis (Table 5; Figure 13). These observations are consistent with national trends.

Figure 12

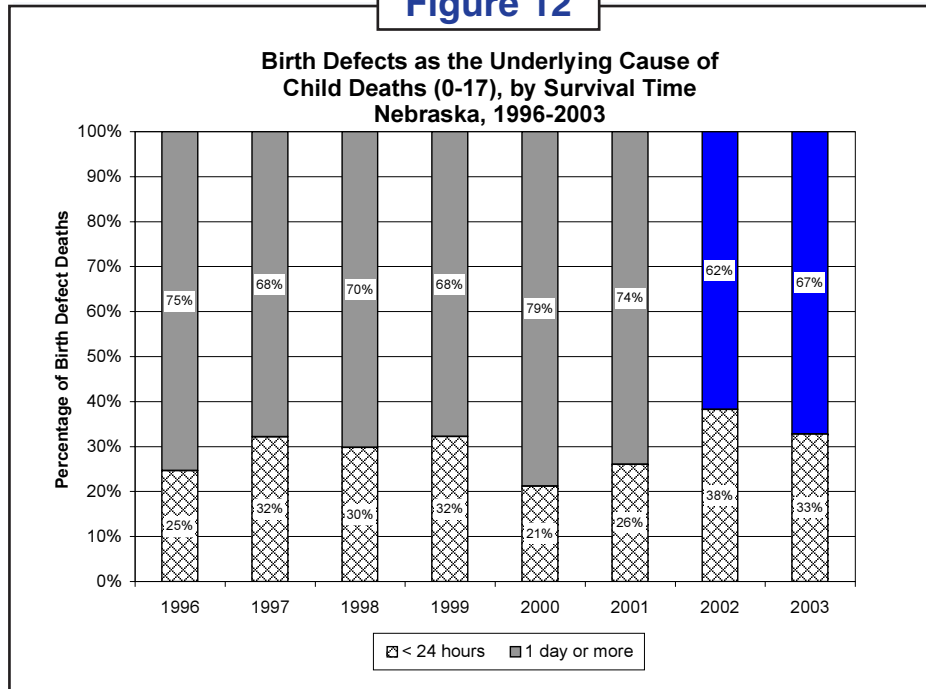
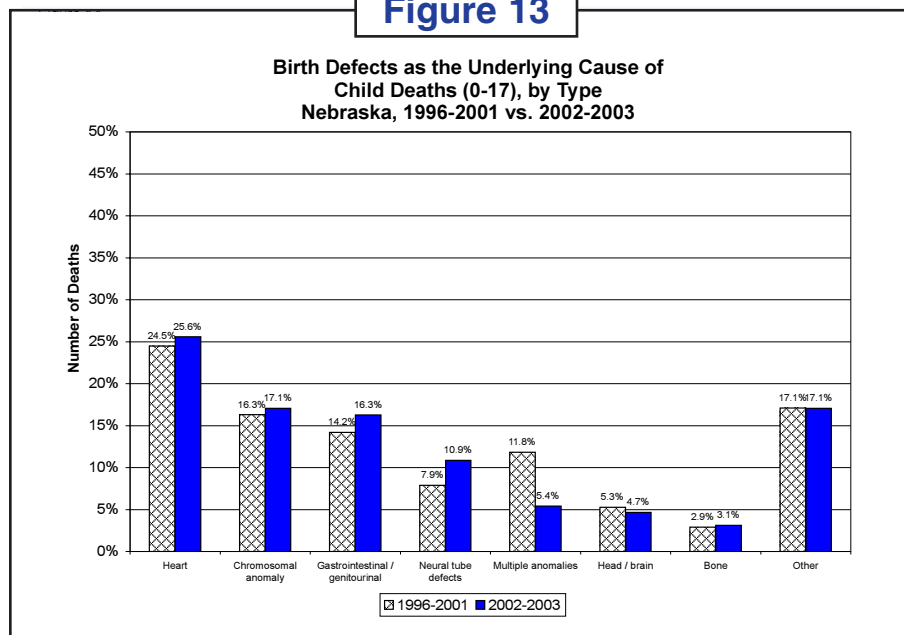


Figure 13



All infants born in the state of Nebraska must have a blood test that screens for eight specific metabolic and genetic diseases. Although cases are rare, early detection allows early treatment of these potentially debilitating or lethal diseases. During 2002 and 2003, 53 Nebraska newborns were diagnosed with a screened disorder. Only one of these children is known to have died during infancy; in that case the parents were not able to adequately follow the treatment regimen for their child's sickle cell anemia. Two children with inconclusive screening results died from causes that appear to be unrelated to metabolic conditions.

Discussion. Nationally, about 1 in 30 babies is born with a birth defect. In Nebraska, the rate during 2002-2003 was approximately 1 in 40. The causes of most birth defects, including chromosomal anomalies, are unknown. However, women who do not take multi-vitamins, who use alcohol, tobacco or other drugs, who are overweight or who have diabetes are at higher risk of having a child with birth defects. Since 1998, folic acid enrichment of cereal grains sold in the U.S. is thought to have decreased neural tube defect rates by approximately 50%. Nevertheless, individual protection is still best achieved with pre-pregnancy multi-vitamin use. Further, the use during pregnancy of ACE inhibitors, a widely used class of anti-hypertensive drugs, has recently been linked to major congenital anomalies in newborns. Prior to conception, all women should review their medication list with their health care provider.

Nationally, approximately one percent of infant deaths is thought to be related to metabolic disease. Nebraska's newborn screening program has used tandem mass spectrometry (MS/MS) to screen for metabolic disorders since 2002, allowing detection of more than 20 additional disorders beyond the required eight. All parents are offered the opportunity to receive the additional screens. By the end of 2005, over 97 percent of parents were opting to have their newborns screened for the full panel.

Nationally, Down syndrome (Trisomy 21), Edwards syndrome (Trisomy 18) and Patau syndrome (Trisomy 13) are the most commonly occurring chromosomal anomalies. However, the survival rate for children with Down syndrome is considerably higher than that of the others and thus the actual number of deaths is quite low. In contrast, infants born with extra copies of chromosomes 13 or 18 have a much less favorable outlook and most die during their first year. Nationally, about 2 in 5,000 babies are born with either Trisomy 13 or Trisomy 18, similar to the Nebraska incidence rate of approximately 1.4 per 5,000 births (2002-2003). Increasing maternal age is the only commonly accepted risk factor for most trisomies, although the majority of these births actually occur to younger women.

➤ Recommendations

State Policy Makers: *Additional resources for the Nebraska Birth Defects Registry would allow it to more effectively and accurately meet the state's needs.* A well-functioning registry monitors birth defect occurrence, causation and related illness and mortality, provides data-based decision making for prevention activities, and monitors the provision of services to children living with congenital anomalies.

Providers: *Every effort should be made to accurately identify and report congenital anomalies at birth, whether or not they are lethal.* Accurate and early detection of defects and anomalies will help ensure that the child receives appropriate medical care. It also allows better forecasting of future need by schools and other systems that serve children with disabilities.

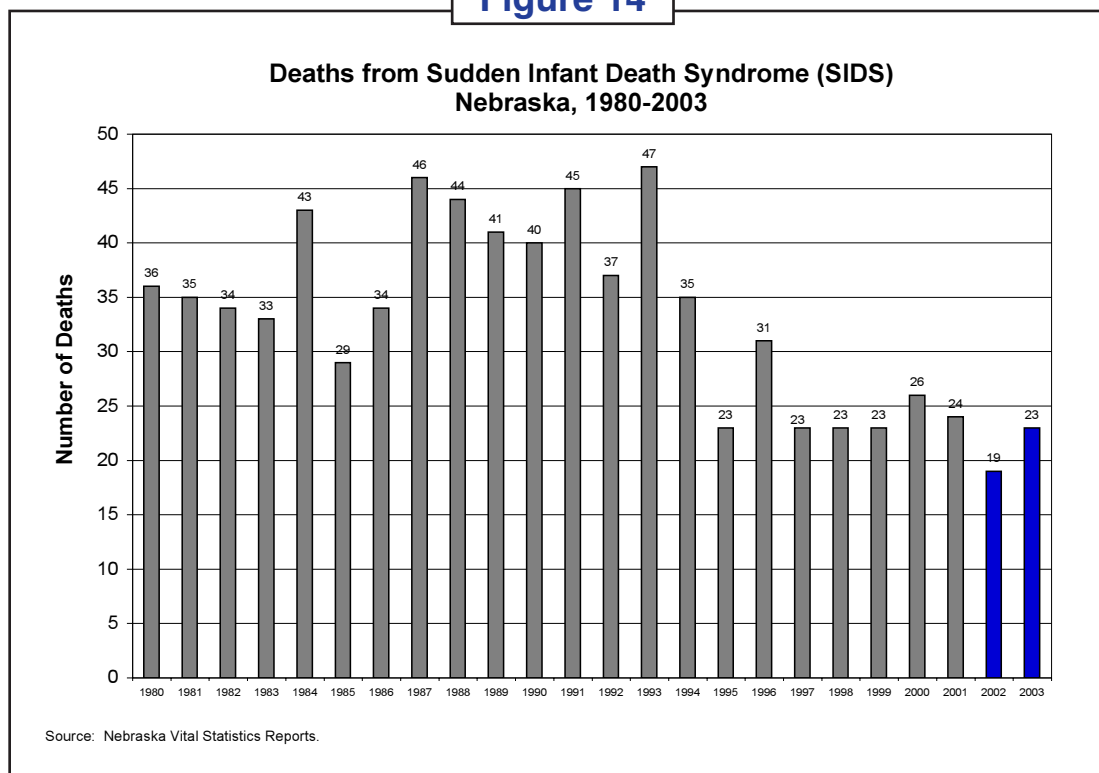
Communities and Families: *Women of child-bearing age, whether or not they plan on becoming pregnant, should consume a daily multi-vitamin containing 400 micrograms of folic acid.* For folic acid supplementation to be effective, women should be taking it before they become pregnant as neural tubes close within the first four weeks of gestation. Folic acid may also prevent other birth defects, such as cleft lip/cleft palate and some heart defects.

Early and regular prenatal care is one of the best ways to promote a healthy pregnancy. During preconception and prenatal care visits, women can discuss with their health care provider the risks to the fetus from certain foods, lifestyle and environmental exposures, as well as any immunization needs.

Sudden Infant Death Syndrome (SIDS) / Sudden Unexpected Infant Death (SUID) - Key Findings

The reduction in Sudden Infant Death Syndrome (SIDS) that began around the early 1990s is one of the nation's public health successes. Nationally, the rate of SIDS dropped by 50% between 1983 and 2003. Similarly, Nebraska's high of 47 cases in 1993 (20.3 deaths per 10,000 live births) dropped to 23 in 2003 (8.9/10,000), although the decline appears to have leveled off (Figure 14). National and local "Back to Sleep" campaigns that encourage caretakers to put infants to sleep on their backs are credited with a large part of these declines.

Figure 14

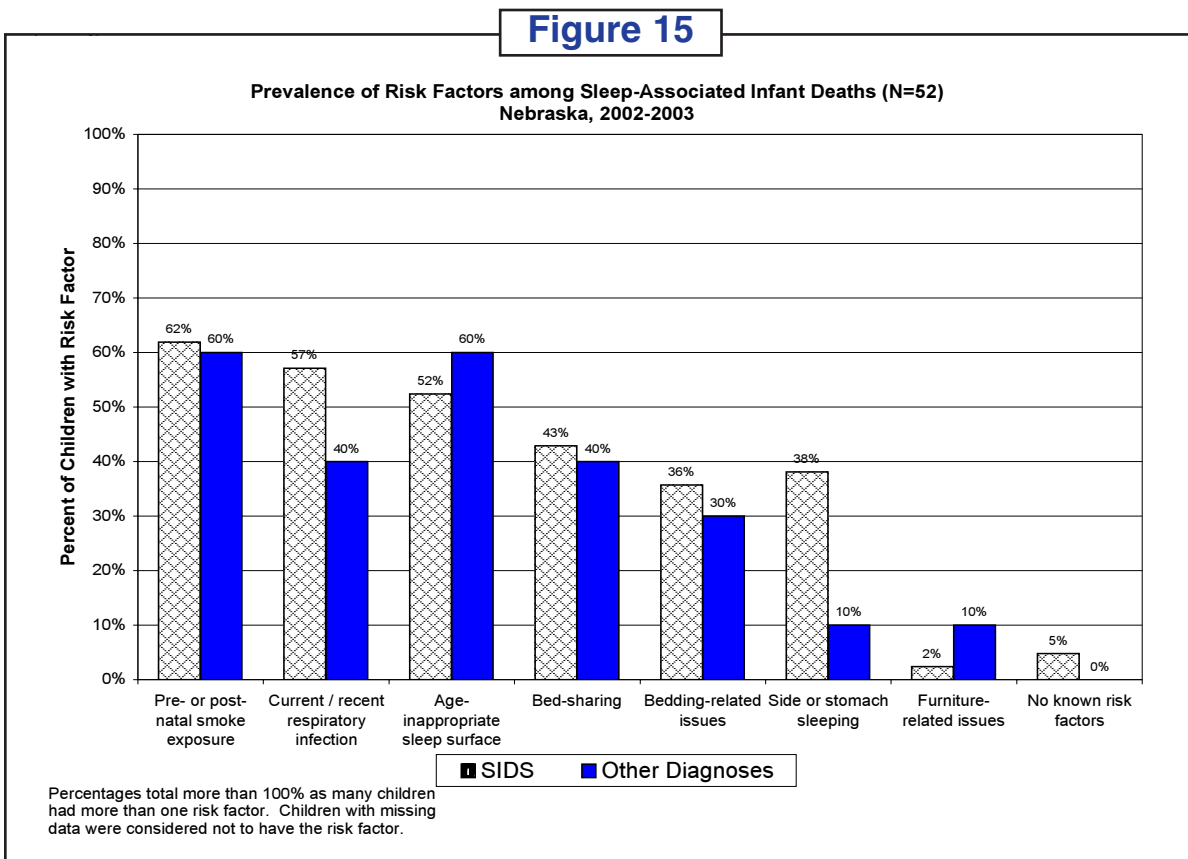


However, concerns have been raised locally and nationally that cases of unintentional suffocation, metabolic disorders, other known medical causes of sudden death and even homicide may be misdiagnosed as SIDS. There are also concerns that the decision process to distinguish among these causes is not uniform across the state; both of these tendencies would artificially affect SIDS rates. To address these concerns, the Team added an additional classification of Sudden Unexpected Infant Deaths (SUID) to this report. This category allows for examination of major risk factors associated with all sleep-associated sudden infant deaths, bypassing inconsistencies in assigning an official cause of death.

A total of 10 infants who died in their sleep were not diagnosed as SIDS, but their incidents shared basic characteristics with the 42 official SIDS cases. Their causes of death were reported as pneumonia (one case), bronchitis/bronchiolitis (three cases), "accidental suffocation or strangulation in bed" (one case) and "undetermined" (five cases).⁴

⁴ The four pneumonia and bronchitis/bronchiolitis cases are also reported in the "Other Medical Conditions" section of this report; the five undetermined cases are included in the "Undetermined" section, and the suffocation death is also included in the "Unintentional Injuries" section.

The 52 total sleep-associated deaths (2002-2003) had similar characteristics regardless of actual diagnosis (Tables 6-7). Cases were more likely to be male (59.6% male versus 40.4% female) and were disproportionately non-White. As was true for the 1996-2001 period, approximately 15% of Nebraska's sleep-associated deaths were known to have occurred while the child was in a child care setting (licensed or unlicensed; Table 8) or with a non-family member babysitter.



Of the 52 total cases, 50 (96.2%) had at least one of the six major risk factors for a sleep-associated death (Table 9; Figure 15).

- Close to two-thirds of the official SIDS (61.9%) and of all sleep-associated infant deaths (61.5%) had documented exposure to tobacco smoke, considerably higher than the most recent estimated statewide smoking prevalences of 27.4% before pregnancy, 14.4% during the last trimester of pregnancy and 19.8% after the birth (PRAMS, 2002).
- Half (53.8%) of the infants were reported to have had respiratory infections, a likely contributor to impaired breathing. Symptoms had not been reported for one of the infants diagnosed by autopsy with a respiratory infection.
- Half (53.8%) of the infants were sleeping in or on something other than a safety-approved crib, playpen or baby bed. Inappropriate surfaces included pillows and adult beds.
- At the time of death, 42.3% of the infants were sleeping with or on an adult or other child. Published estimates of "usual" bed sharing range from 13% to 51%.
- Approximately one-third (32.7%) of the infants had not been put to sleep on their backs, similar to a recent statewide estimate of 29.5% (PRAMS, 2002).

- One-third (34.6%) of the infants were reported to have been sleeping with large pillows or loose bedding including extra quilts or blankets.
- The two cases with "furniture-related" risk factors involved a baby found with her face wedged between a bunk bed mattress and the wall (diagnosed as SIDS), and a baby found with a blanket wrapped around his face (diagnosed as accidental suffocation).

Discussion. The similarities between the official Sudden Infant Death Syndrome (SIDS) cases and the 10 additional sleep-associated deaths underscore both the importance of autopsies and inconsistencies in the use of the SIDS diagnosis. The American Academy of Pediatrics defines SIDS as the sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history.⁵ However, two of the 2002 and 2003 SIDS deaths were not autopsied, two had only a minimal police investigation and one was not investigated at all, compounding the difficulty of understanding what actually happened.

Public health campaigns have begun addressing multiple sleep-related safety issues rather than having a sole focus on SIDS prevention. The factors shown in Table 9 are associated with an increased risk of accidental suffocation of infants, who may not be physiologically mature enough to overcome otherwise minor challenges to their breathing, particularly during sleep. Promoting "Safe Sleep" rather than the more narrow "SIDS prevention" increases the number as well as types of deaths that may be averted.

However, many of the emerging risk factors are controversial. For example, bed-sharing advocates promote the increased ease of breastfeeding and of comforting a cranky baby when infants sleep in the same bed as their parents; the actual amount of risk associated with the practice continues to be studied. Yet, even traditional SIDS risk factors are still at play in Nebraska. Surveys of Nebraska mothers continue to show that the "Back to Sleep" message has been less successful in some racial and ethnic communities than others; such campaigns may need to adapt their messages to better reach diverse caretakers.⁶ Prenatal and infant exposure to cigarette smoke also remains a problem. The Nebraska Legislature has prohibited or restricted smoking in licensed child care and preschool settings, and home-based settings when client children are present.⁷ However, in 2001, 15% of Nebraska mothers reported that they smoked during the last three months of their pregnancy and 10% reported that their newborns were exposed to tobacco smoke.

Although the scientific understanding of sudden infant death continues to evolve, in 2005, the American Academy of Pediatrics (AAP) issued a revised SIDS risk reduction policy statement based on the best available evidence.⁸ Key points are:

- **Infants should be placed wholly on their back for every sleep.**
- **The best sleeping surface** is a firm crib mattress, covered by a fitted sheet.
- **Keep soft objects and loose bedding out of the crib.** Pillows, quilts, comforters, sheepskins, stuffed toys and other soft objects should not be around a sleeping infant.
- **Do not smoke during pregnancy.** Avoid infant's exposure to second-hand smoke.
- **Bed sharing during sleep is not recommended.** A separate but close sleeping environment is recommended, such as a separate crib in the parent's bedroom.

⁵ LB1113, passed by the Nebraska Unicameral in 2006, requires a death scene investigation and review of the clinical history as well as an autopsy before an infant death can be certified as SIDS.

⁶ Back sleeping in the Nebraska PRAMS survey was reported by 65% of White respondents, 35% of African-American respondents, 64% of Asian respondents, 55% of Hispanic respondents and 59% of Native American respondents (2001 data except for Native Americans which are from 1999).

⁷ Nebr. Rev. Stats. §71-5707; LB 1005 (2004).

⁸ www.aap.org/ncepr/sids.htm.

- **Consider offering a pacifier at nap and bedtime.** Breastfed infants should be at least one month old before a pacifier is used, once breastfeeding is firmly established.
- **Avoid overheating.** Infants should be lightly clothed for sleep. The room temperature should be comfortable for a lightly clothed adult.
- **Avoid commercial devices** claiming to reduce the risk of SIDS. None have shown efficacy or safety.
- **There is no evidence that use of home monitors decreases the risk of SIDS.**
- **Encourage “tummy time”** to avoid development of head flattening (positional plagiocephaly). Avoid having the infant spend excessive time in car-seat carriers and bouncers.
- **Ensure that others caring for the infant are aware of these recommendations.**

➤ Recommendations

State Policy Makers: Regulations for infants in licensed child care facilities should be revised to mandate back sleeping, recognizing the need for a waiver in some situations, and to repeal requirements for “bumper pads” and stuffed toys in cribs. Nationally, 20% of SIDS deaths occur in child care facilities, emphasizing the importance of prevention practices in these settings. This recommendation is in line with positions of national and state advocates, who note that any items in infants’ cribs increase the chances of a SIDS death.

Programs are needed that specifically target smoking among pregnant and postpartum women. Smoking during and/or after pregnancy is a risk factor for multiple infant and childhood illnesses, as well as for sudden infant death. Previous funding for such programs that resulted from a recommendation made by the Governor’s Blue Ribbon Panel on Infant Mortality (2000), and needs to be restored and expanded.

A standardized death scene investigation should be conducted for all unexpected child deaths. Doll reenactments should be part of the investigative protocol for sleep-related infant deaths. A thorough investigation improves understanding of the events surrounding the death, and can help dispel suspicions of possible caretaker malfeasance. Doll reenactments are valuable tools to help witnesses describe the body and face position of the infant when found.

Community Organizations and Child Advocates: Existing SIDS prevention regulations, messages and initiatives should be expanded to include other “Safe Sleeping” issues and options. These messages should include the AAP recommendations (below), and be tailored to racially, ethnically, culturally and financially diverse audiences. Additional emphasis is needed on including grandparents and other extended family members as targets of safe sleep messages.

“Safe Crib” programs have been successfully implemented in communities around the country to provide low income families with cribs that meet current safety standards.

Parents: Infants should be placed wholly on their back for every sleep.

Breastfed infants appear to have lower risks of sudden death.

The American Academy of Pediatrics (AAP) does not recommend bed-sharing during sleep. The recent AAP policy statement asserts that, “Infants may be brought into bed for nursing or comforting, but should be returned to their own crib or bassinet when the parent is ready to return to sleep. However, there is growing evidence that room sharing (infant sleeping in a crib in parent’s bedroom) is associated with a reduced risk of SIDS. The AAP recommends a separate but close sleeping environment.”

Cancer / Malignant Neoplasms - Key Findings

Childhood cancer is not one disease, but rather a spectrum of different malignancies with different causes. Leukemia and brain tumors were the most common causes of child cancer deaths in Nebraska as well as nationally. Although overall the number of child cancer deaths dropped during 2002 and 2003 (Table 10), cancer remained the most common cause of disease-related mortality.

Discussion. National statistics show that childhood cancer kills more children each year than asthma, diabetes, cystic fibrosis and AIDS combined. However, new treatment options have greatly improved overall survival rates over the last several decades. The cause of most childhood cancers is unknown. A few conditions such as Down syndrome, other specific chromosomal and genetic abnormalities, and ionizing radiation exposures explain a small percentage of cases. Recent research suggests an association between maternal vitamin intake during pregnancy and a lower occurrence of certain childhood brain tumors. However, environmental and non-medical causes of childhood cancer have been difficult to demonstrate conclusively.

➤ Recommendations

Families, Health Care Providers and Health Educators: *Providers should stay up to date on findings regarding risk factors for, causes of and treatments for childhood cancers.*

Infectious, Chronic and Other Medical Conditions

The 44 “other” medical cases (Table 11) cover a wide range of causes. Infectious disease-related deaths in infants at least one week old and who were not preterm are included here, recognizing that there is some overlap with pregnancy-related conditions. However, children who died from complications of maternal infections, e.g., HIV or herpes virus, are considered in the Pregnancy-Related section, again recognizing the overlap between categories.

Influenza is typically the leading cause of vaccine-preventable death in children. However, many of the children’s medical records and/or death certificates merely listed the cause of death as “pneumonia” without specifying a specific causal agent. It was thus not possible to quantify the number of fatal influenza cases among the 10 known pneumonia and bronchitis-related deaths.

There was one reported child death from asthma in each of the two years studied (Table 11). This compares favorably to the average of nearly three deaths per year during the 1996-2003 period. One child was treating his symptoms with over-the-counter allergy medications; there was no evidence that either he or his family had recognized his asthma. The second death occurred to a teen who regularly used her inhaler.

Discussion. Children with chronic allergies should always be evaluated by a physician to check for symptoms of asthma. Asthma deaths can occur in children with either mild, moderate or severe persistent asthma; there is no relationship between severity and the risk of an asthma-related death. Recent studies have shown that regular use of inhaled corticosteroids will decrease asthma deaths. Reliance on albuterol inhalers and emergency injectors is a warning that a child’s asthma is not being properly controlled.

There were no reported deaths during 2002 and 2003 from the once common, vaccine-preventable infectious diseases - polio, chickenpox (varicella), measles, mumps, rubella, diphtheria, tetanus, pertussis, or hepatitis B. The organisms that cause these diseases have not disappeared, however, and both the diseases and related deaths will reemerge if vaccination coverage drops. In 2003, 75.3% of Nebraska two-year olds had received the chickenpox vaccine, lower than the national average of 84.8%. Children who are not vaccinated risk getting the disease as adults when complications are more severe. Complications from chickenpox can include bacterial infections, pneumonia, dehydration, central nervous system problems and death.

➤ Recommendations

State Policy Makers: A statewide registry to track immunizations would allow for better development of prevention strategies against existing and emerging diseases.⁹ Currently, multiple registries exist but cover only select parts of the state's population and are not coordinated with each other. A comprehensive registry would include public and private providers, improve access to records for families who move or change providers, and enhance the ability to examine trends and gaps in immunization coverage.

Communities: There are many resources available to help improve community health and prevent infectious disease. For example, the Guide to Community Preventive Services addresses the effectiveness of three population-based strategies to increase vaccination coverage: 1) Increasing community demand, 2) Enhancing access to vaccination services, and 3) Provider-based interventions.

Providers, Communities and Parents: Shortness of breath and wheezing indicate the need for prompt medical attention. Asthma is a serious disease that remains undetected in too many people, and may be misdiagnosed as allergy. Each year many people who were never aware that they had the disease die from complications of an acute asthma attack.

Children with persistent asthma should be taking a daily prevention medicine, the most effective being inhaled corticosteroids. Reliance on albuterol-based inhalers in an emergency should not be considered effective control of asthma. Frequent use of albuterol inhalers or an emergency injector, disturbed sleep or a decrease in activity levels are warnings that a child's asthma is not being properly controlled. A customized, written asthma action plan developed in conjunction with the child's medical provider should be on file at the child's school and/or child care facility.

The Centers for Disease Control and Prevention (CDC) now recommend influenza vaccine for healthy children ages 6 to 23 months. These changes are the result of recent reports demonstrating that otherwise healthy young children aged 6 to 24 months are hospitalized for influenza and its complications at rates comparable to those for whom influenza vaccination is already recommended, including pregnant women and the elderly.

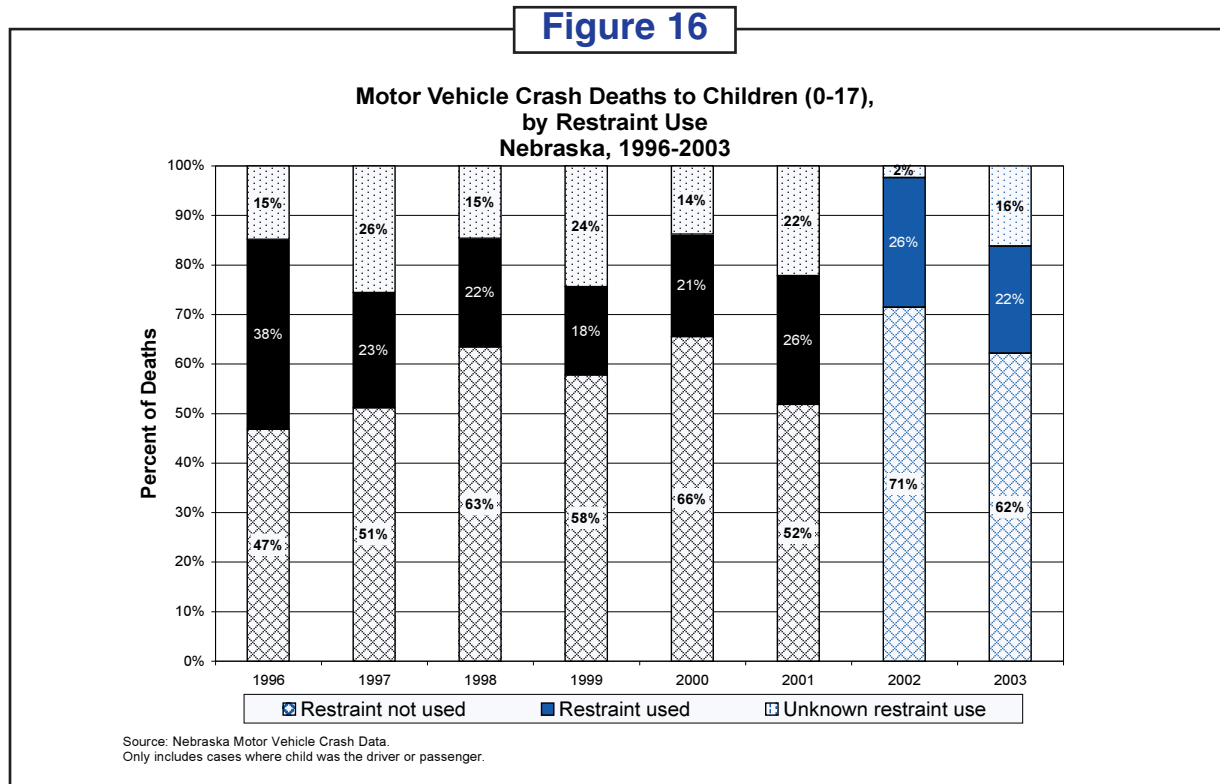
Parents should consult their providers about which vaccines their children should have and when, and keep track of their children's immunization status. The Centers for Disease Control and Prevention (CDC) consider vaccinations some of the most important tools available for preventing disease. Vaccinations not only protect children from developing a potentially serious disease but also protect the community by reducing the spread of infectious disease.

Motor Vehicle-Related Incidents - Key Findings

The third most frequent cause of death to Nebraska's children during 2002 and 2003 involved motor vehicles in traffic situations. Several of these deaths occurred out of state and details were not available. However, at least 77 children were killed while in a motor vehicle either as a driver or passenger, representing 83.7% of all motor vehicle-related deaths to children (Table 12). An additional seven children (7.6%) were struck and killed by motor vehicles while they were walking or riding a bicycle. Four children were killed when the motor home in which they were riding caught fire. Three children were killed in all terrain vehicle (ATV) incidents, two while riding and one when his father lost control of the ATV in the family's driveway. One young driver was killed at a railway crossing when she did not notice a second train coming from the opposite direction.

⁹ LR 406 (2006) authorizes a study to examine and provide recommendations relating to a statewide immunization registry. The study will be reported back to the Nebraska Unicameral.

Information on the use of restraints (safety belt or child safety seat) was not available for 12% of the incidents. However, at least 67.5% of the children killed in car crashes were documented as either having been unrestrained or ejected from the vehicle (Table 12). This is consistent with statewide motor vehicle crash data showing an overall increasing trend of deaths of unrestrained children (Figure 16).



Statewide, the involvement of alcohol in crashes where children were killed decreased from 21.7% in 2002 to 19.1% in 2003, but because official definitions changed in 2001 the direction of the long term trend is not clear. Data were not available to consistently determine whether the alcohol use was by the child, someone else in the child's vehicle, or a person in a different vehicle involved in the crash. However, nationally, nearly two-thirds of children age 15 and younger who died in alcohol-related motor vehicle crashes were riding with the drinking driver.

Discussion. The vast majority of motor vehicle incidents were preventable - attributed to driver error or poor judgement. The low rate of restraint use was clearly a factor in these incidents becoming fatalities. A recent Child Trends report discusses several risk factors for fatal crashes among adolescents, including a lack of experience, a propensity for risk taking, and even incomplete brain development; the report goes on to discuss new programs and legislation.¹⁰ However, many deaths could be prevented through better application of safety measures and improved enforcement of existing laws. The Nebraska Injury Prevention State Plan provides a comprehensive assessment of motor vehicle injuries and recommendations to prevent future injuries. For more information contact the Injury Prevention Program, Nebraska Health and Human Services System.¹¹

¹⁰ <http://childtrendsdatabank.org/pdf/teen%20driving.pdf>.

¹¹ 402/471-2101; <http://www.hhs.state.ne.us/hpe/injury.htm>.

➤ Recommendations

State Policy Makers: Nebraska's safety belt law should be upgraded to primary (standard)

enforcement. States with primary enforcement laws have a safety belt usage that is estimated at 15% higher than those without. Safety belts cut the risk of death or serious injury in a crash by 45 to 50%. Children riding with unrestrained drivers are much more likely to be completely unrestrained compared to children riding with belted drivers.

Child endangerment laws should be considered that provide special sanctions for drivers convicted of DUI with a child in the vehicle. Currently, 33 states have such laws. Mothers Against Drunk Driving (MADD) cites research showing that "A child in a vehicle with a drinking driver is not only at risk from the impaired driver, but also from the lack of safety restraint use..., as drinking drivers are much less likely to make sure a child is properly restrained."

Upgrade Nebraska's graduated licensing provisions. Research shows that unsupervised driving with teenage passengers increases crash risk compared with driving alone - the more passengers the greater the risk. Provisions that would make Nebraska's graduated licensing more effective include:

- Requiring at least 10 hours of nighttime driving as part of the required 50 hours of supervised drive time; and,
- Limiting the number of teenage passengers to one or none during some or all of the intermediate phase, when an adult is not present.

Communities: Existing laws that all children ages six to 18 use a seatbelt in all seating positions should be enforced. Parents must impress upon teens the importance of wearing safety belts every time they drive or ride in a vehicle. The 2003 Nebraska Youth Risk Behavior Survey (YRBS) indicated that only 56.6% of teens surveyed usually wore a safety belt when riding in a car driven by someone else.

Parents: Parents should limit the number of teenage passengers a teen driver may carry. Children should always use age-appropriate restraints when in a motor vehicle:

- **Child safety seats.** When used correctly, child safety seats reduce the risk of death by 71% for infants and by 54% for children ages 1 to 4.
- **Child booster seats.** A child who has outgrown a child safety seat (generally at 40 pounds) should use a booster seat until approximately age 8 or 80 pounds and/or 4'9" tall. Children ages 4 – 8 years old are four times more likely to suffer a serious head injury when restrained only by a safety belt as compared to children who used child safety seats or booster seats.
- **Safety belts.** For children who are large enough to fit in them properly, safety belts reduce the risk of death or serious injury in a crash by 45 to 50%.

Children age 12 years and younger should not ride in the front seat. Children are at risk of injury from front passenger-side airbags; rear seats are the safest part of a vehicle in the event of a crash. Riding in the back seat is associated with a 46% reduction in the risk of fatal injury in cars with a front passenger-side airbag and at least a 30% reduction in the risk of fatal injury in cars without one.

Bicycle helmets should be worn by all persons (i.e., bicycle operators and passengers) of any age whenever and wherever they ride a bicycle. Bicycle helmets reduce the risk of serious head injury by as much as 85% and the risk of brain injury by as much as 88%.

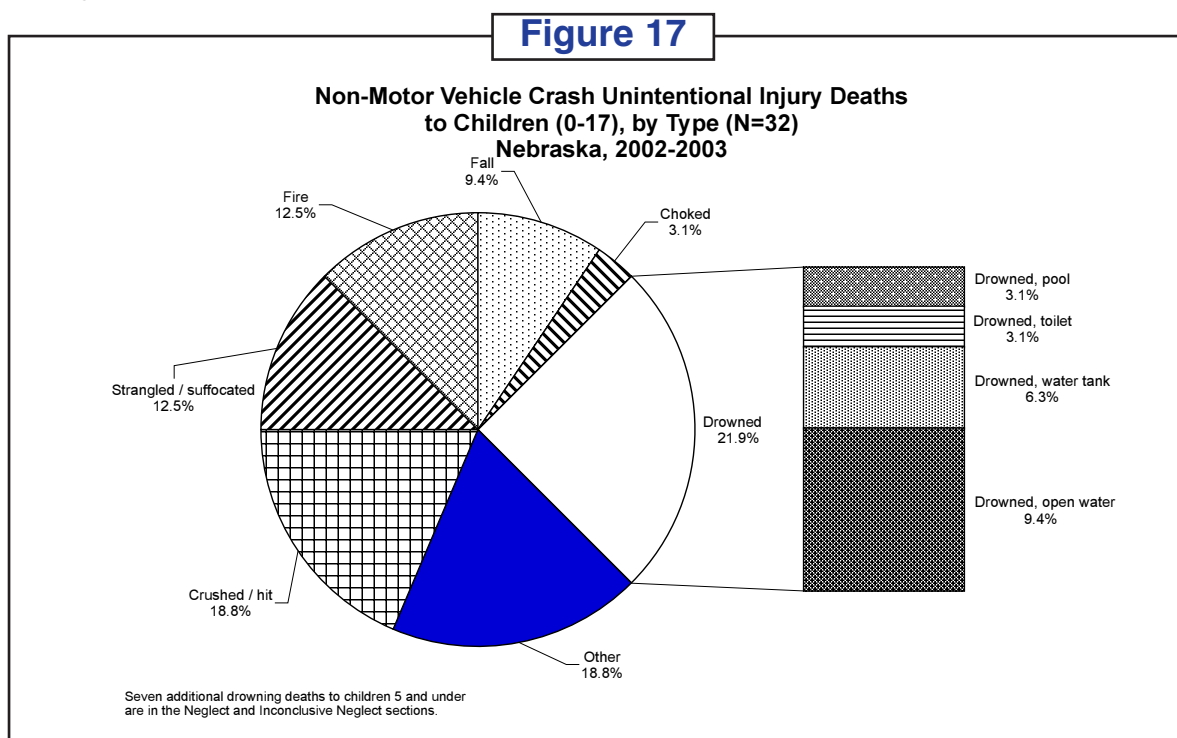
Teach children pedestrian safety. The most important thing parents can do to teach their children safe pedestrian behavior is to practice it themselves: crossing streets at corners, using traffic signals and crosswalks whenever possible, and making eye contact with drivers prior to crossing in front of them.

Parents should be aware of the high potential for serious injury and even death when ATVs are ridden or operated by children under 16. ATVs should be operated only on designated trails, not on public roads, paved surfaces or fields. Personal protective equipment for ATV operators should include a U.S. Department of Transportation-approved helmet with face protection, goggles (if the helmet does not have face protection), a long-sleeved shirt or long pants, non-skid boots and gloves. However, the national Safe Kids organization concludes "...there is simply no way to make ATV riding a safe activity for children."

Unintentional Injuries - Key Findings

Drowning

The most common cause of non-motor vehicle-related, unintentional injury death was drowning, accounting for 21.9% of the 32 total unintentional injury deaths (Table 13; Figure 17). Three of these occurred to children and youth swimming in lakes and rivers. One death of an infant who drowned in a toilet was included in these unintentional injuries. However, seven additional drowning deaths to children under five are included in the Caretaker Neglect sections.



Discussion

Safe Kids USA states that, "While water recreation provides hours of enjoyment and exercise for children, water and children can be a deadly mix when an unsafe environment, inadequate supervision or improperly used safety gear is also present. Nationally, drowning remains the second leading cause of injury-related death among children ages 1 to 14.

Drowning can occur in a variety of circumstances – during water recreational activities (such as swimming and boating) or when a young child is left unsupervised for a short time in the bathtub or around the home with access to nearby pools and spas. Drowning, which can happen in as little as one inch of water, is usually quick and silent. A child will lose consciousness two minutes after submersion, with irreversible brain damage occurring within four to six minutes. The majority of children who survive without neurological consequences are discovered within two minutes of submersion, and most children who die are found after 10 minutes.

Research shows there is no one device or solution that can prevent all childhood drownings. Instead, a multifaceted strategy, including active supervision by a designated adult, safe water environments, proper gear and education, is required to ensure children's safety in and around water."¹²

Fire

Four children were killed in three separate home fires. Unattended cigarettes caused one of the fires, one began in the laundry room, and one was possibly started by a child playing with a cigarette lighter (Table 13).

Discussion. According to the U.S. Fire Administration (USFA), "Nearly half of all children have engaged in fire play. While the majority of the child-set fires are set out of curiosity, not malice, the damage they cause, both in economic and human costs, are real and devastating." The USFA's *Fire Safety Campaign for Babies and Toddlers* is a public awareness and education campaign designed to draw attention to the increased risk of fire death for young children, and to teach parents and caregivers how they can avoid the tragedy. The campaign's slogan: "Prepare. Practice. Prevent the Unthinkable." urges parents and caregivers to prepare by installing and maintaining working smoke alarms; safely storing lighters and matches out of children's reach and sight; and practicing a fire escape plan with children, which should include helping toddlers understand how to quickly respond in case of fire, and planning how adults can escape with babies.

The Nebraska Fire Marshall's Office notes that many people do not understand potential risks involved in laundry issues - dryer overloading, failing to clean lint from the dryer, using plastic vent hose for dryer vents, failing to let clothes complete the cool down cycle prior to removal and folding, attempting to get stains such as oil or grease out of clothing using flammable liquids in the washing machine, failing to measure laundry detergent, piling clothes or setting bleach next to the hot water heater, and not venting the dryer to the outside of the home (potential carbon monoxide poisoning).

Even though home fires are rare, it is crucial to be prepared. Escape routes need to be practiced with both adults and children; younger children are more likely to try and hide from a fire than to try and escape. Adults send the wrong message to children when they disable or do not maintain smoke alarms.

Other

Only one child was killed in this period during unsupervised play with firearms; none were killed in incidents with farming machinery. However, five children were killed in driveways by cars backing up or by a vehicle inadvertently put into gear (Table 13). One teen was tubing at a lake when she was hit in the back by a 14-year old illegally operating a jet ski. This incident was a major impetus for changes to Nebraska's State Boating Act, including a minimum age for boat drivers and restrictions on the activity of personal watercraft (includes jet skis). Remaining unintentional injury deaths were isolated incidents, most of which were preventable using basic safety precautions.

Discussion. The Kids and Cars program¹³ estimates that nearly half (46%) of nontraffic, non-crash vehicle fatalities involving children under 15 were caused by motor vehicle backovers. Children are very quick, small and

¹² <http://www.usa.safekids.org/NSKW.cfm>.

¹³ <http://www.kidsandcars.org/>

easily out of sight when in front of or behind a motor vehicle, particularly as personal vehicles get larger and longer and their "blind spots" correspondingly larger. Adults operating motor vehicles or farm machinery can not adequately monitor the whereabouts and movements of young children.

In contrast to the one reported unintentional firearm death during this period, the Nebraska Hospital Association reports 102 firearm-related hospitalizations of children during 2002 and 2003. Home firearms should always be stored safely. Lists are available of firearm safety devices that have been tested and approved by the state of California.¹⁴ Local law enforcement agencies also have access to trigger locks for community giveaway programs.

➤ Recommendations

Communities: *Communities are encouraged to implement smoke alarm distribution, firesetter prevention and fire intervention programs.* Homes with working smoke alarms typically have a death rate that is 40% to 50% less than for homes without them. The Juvenile Firesetter Intervention Program, available through the Nebraska Fire Marshal's Office, strives to intervene with children who play with or deliberately set fires as well as effectively teach fire prevention to the community. Family-oriented videos are also available for agency use.

Parents: *When near a pool or body of water, parents and other caretakers should always designate one adult to keep sight of all children, at all times. A child should never be unsupervised in or near water, even shallow wading pools.* Devices such as "water wings" can not be relied upon to keep children afloat and alive. Young children can drown in as little as one inch of water, very quickly.

Young teens should not be left alone in potentially hazardous situations such as when swimming in lakes and rivers. The ability to swim does not replace the need for supervision, even into the teenage years.

Smoke alarms should be installed and maintained on every floor of a home. Smoke alarms are recommended in each sleeping room. Alarms need to be tested frequently and the batteries replaced at least once a year. The entire alarm should be replaced every 10 years as the sensors wear out even though the alarm will still sound when tested. Devices are currently available to assist individuals with sight and/or hearing impairment to recognize warnings provided by smoke alarms.

Family discussions on fire safety will help familiarize young children with what to do during a fire, including practicing an escape plan. These discussions can also help adults recognize and correct any hazards that would delay or block escape.

*Backup cameras installed on the rear of vehicles reduce or eliminate "blind spots" behind the vehicle, which can range from five to over 30 feet for normal size adult drivers.*¹⁵

Eliminate potential safety hazards for young children. Thorough home "child-proofing," from a child's perspective, can avoid needless tragedies. Safety, not convenience, should be the first consideration when child-proofing the home. Toilet lids should be kept shut; toilet locks may be helpful.

*Parents and caregivers should be aware of the types of foods and objects that pose a choking risk for children, become familiar with methods to reduce this risk, and be able to treat choking in children.*¹⁶

¹⁴ <http://caag.state.ca.us/firearms/devices.htm> or <http://justice.hcdcdojnet.state.ca.us/safetydevice/allmakes.pdf>.

¹⁵ <http://www.kidsandcars.org/>.

¹⁶ <http://www.heimlichinstitute.org/howtodo.html#infantAnchor>.

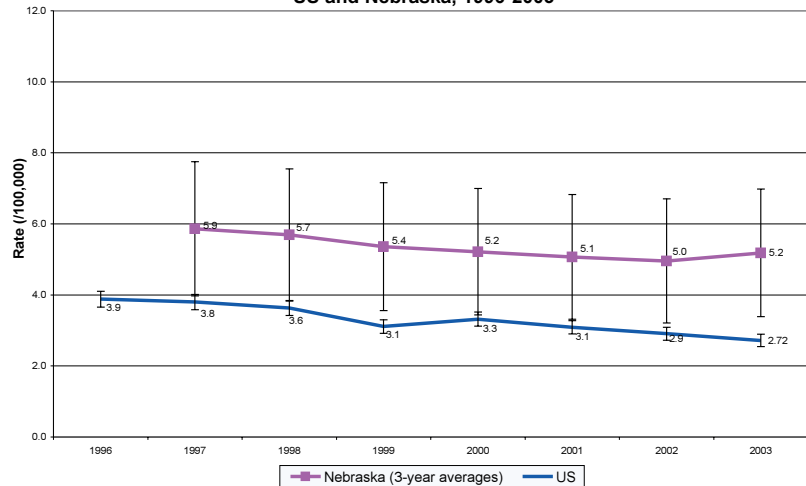
Suicide - Key Findings

Over the period 1996 to 2003, suicide rates for Nebraska children ages 10 to 17 declined slightly. However, while the actual number of deaths is relatively small, Nebraska's rates were statistically significantly higher than national rates for two of those years (Figure 18). During 2002 and 2003, at least 22 children ranging in age from 11 to 17 and resident in 14 Nebraska counties took their own lives (Table 14; Figures 19-20). The vast majority of the suicides were boys (86.4%) with the most common age being 17 (31.8%); only three (13.6%) of the suicide victims were girls (Figure 20). Forty-one percent of the children used a firearm to commit suicide (Table 14). Cases reviewed by the Team tended to fall into three groups:

- Youth with identified mental health issues where the suicide was not a complete surprise;
- Youth with no identified mental health issues but who tended to have trouble in school, lacked a peer group and/or manifested feelings of hopelessness; and,
- Purely situational cases.

Figure 18

**Suicide Rates, Children Ages 10-17
US and Nebraska, 1996-2003**



Nebraska rates are three year averages. The 95% confidence intervals around each point are also shown. Nebraska rates are significantly higher than US rates for 1999, 2002 and 2003 (confidence intervals do not overlap).

Figure 19

**Suicide Deaths to Children (0-17), by County (N=22)
Nebraska, 2002-2003**

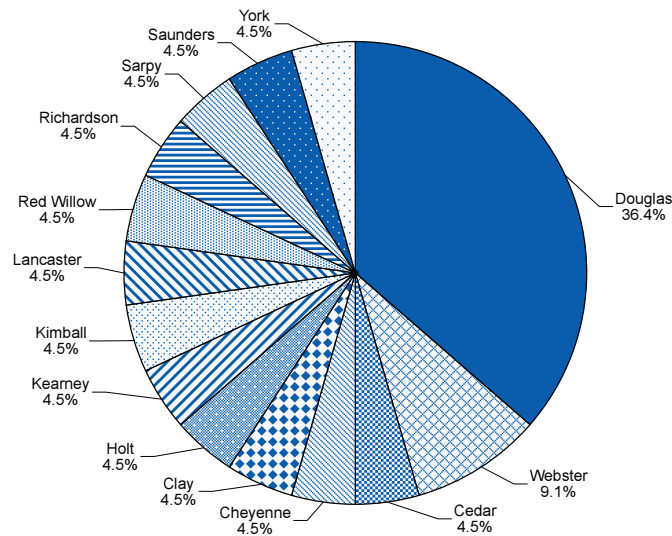
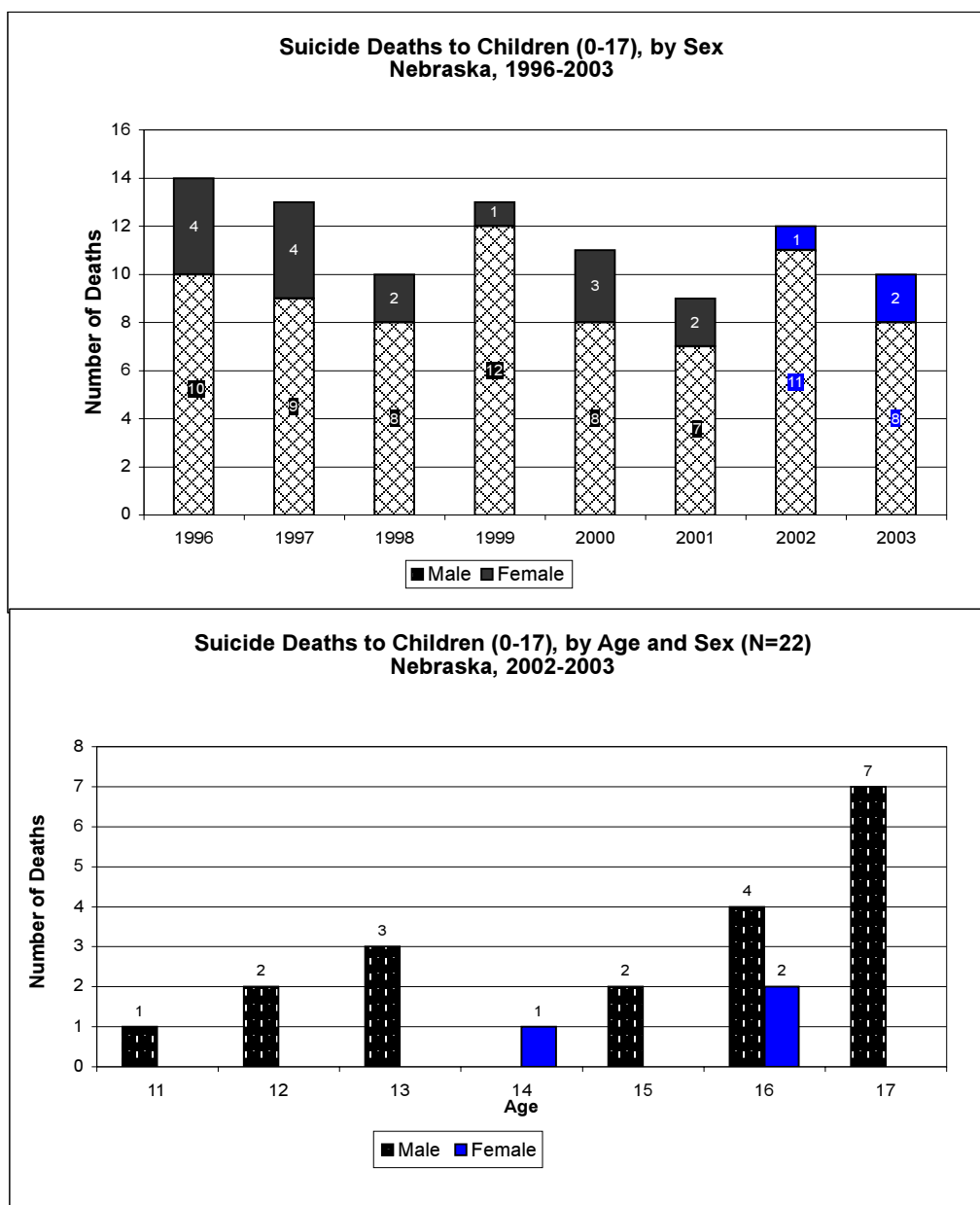


Figure 20



Discussion: In 2002, suicide was the second leading cause of death for children ages 10 to 17 nationwide. The 1999 Surgeon General's Report on Mental Health noted that "Pre-existing mental health problems, availability of firearms, substance abuse, youth-specific stressful life situations, and a focus on the drama of suicide by the news and entertainment industries are all considered factors contributing to the incidence of youth suicide." The Child Death Review Team would like to acknowledge the attention that the Omaha World Herald brought to the problem of youth suicide in Nebraska through a series of articles run in 2005.¹⁷

¹⁷ http://www.omaha.com/index.php?u_pg=528&u_xid=945&u_sid=1409483.

Youth who are lacking a strong support system at home are also particularly vulnerable to experiencing feelings of hopelessness and isolation. Programs that match youth with caring adults who spend time with them and take an interest in them may reduce their feelings of hopelessness and isolation. A growing body of literature points to effective mental health interventions that reduce risk for suicide when youth considering suicide are identified and treated with therapy and medication. All communities and school systems need the ability to screen for and identify youth at risk for suicide and to implement individualized intervention plans when needed.

➤ Recommendations

State Policy Makers and Communities: *All teenagers need access, including financial access, to confidential, professional mental health services.* Co-locating mental health professionals with health care providers or within other non-traditional settings may make youth more comfortable accessing these services.

Funding is needed for community-based adolescent suicide prevention programs. A pilot Gatekeeper Training project was recently implemented in southeast Nebraska that targeted educators, primary care providers, law enforcement officers, and clergy for training on the warning signs, risk factors, and interventions to prevent suicide. This project should be replicated in other areas of the state.

Communities, Schools and Parents: *Broad-based public education efforts are needed to draw attention to suicide as a significant and preventable cause of death for youth, create awareness of signs that indicate risk for individual youth, and encourage help-seeking actions when at risk youth are identified.* Among the many available resources are the National Center for Suicide Prevention Training's on-line workshops on "Planning and Evaluation for Youth Suicide Prevention" and "Youth Suicide Prevention: An Introduction to Gatekeeping".¹⁸ The "Youth Suicide Prevention School-Based Guide" provides user-oriented materials for schools to address this difficult topic, evaluate their prevention efforts, and assist in developing partnerships with communities and families.¹⁹

Parents: *Any suicidal gesture, no matter how "harmless" it seems, demands immediate professional attention.* Parents need to be aware of signs and symptoms of depression and/or suicidal ideation in teenagers and not be afraid to talk to their children about them. No talk of suicide should be taken lightly.

Parents who keep firearms in the home must understand the importance of storing unloaded firearms and ammunition in separate, locked and inaccessible locations.

¹⁸ <http://www.ncspt.org/about.asp>.

¹⁹ <http://theguide.fmhi.usf.edu/>.

Twenty-eight children suffered violent, abusive or neglectful deaths during 2002 and 2003; children under five and older teenagers were at highest risk (Table 15; Figure 21). Eight children between the ages of 12 and 17 were shot (n=6), stabbed (n=1) or strangled (n=1) in disputes with friends or peers; the manner of death in the remaining case of peer assault is unknown (Table 15, Figure 22). These deaths occurred in Douglas (n=7), Lancaster (n=1) and Scottsbluff (n=1) counties; five (55.6%) of the nine victims were female.

Of the 19 children not killed by peers, six died from Shaken Baby / Shaken Infant Syndrome (21.4%; Table 15, Figure 22). Four (14.3%) died from blunt force trauma, e.g., having their head hit against a hard surface, and one child (3.6%) died from chronic physical abuse. Two toddlers died after being forcibly held in scalding water as a punishment and two were caught in adult gun violence.

Also among these 19 deaths are a seven year old child who drowned in a hotel pool (criminal child neglect), a four year old who suffocated in the trunk of a car (misdemeanor child abuse), a 10 year old child who died from the long term effects of blunt force trauma at age two, and a four year old boy whose father confessed to his murder but whose body was never found. Twelve of these 19 victims were male (63.2%).

Discussion – Youth Violence: Nationally, homicide is the third leading cause of death for children ages 10 to 17. For older teens (15-17), it is second only to motor vehicle accidents as a cause of death. The presence of guns turns “normal” adolescent conflicts into violent confrontations resulting in serious injury or death. Common risk factors for adolescent gun violence include:

Figure 21

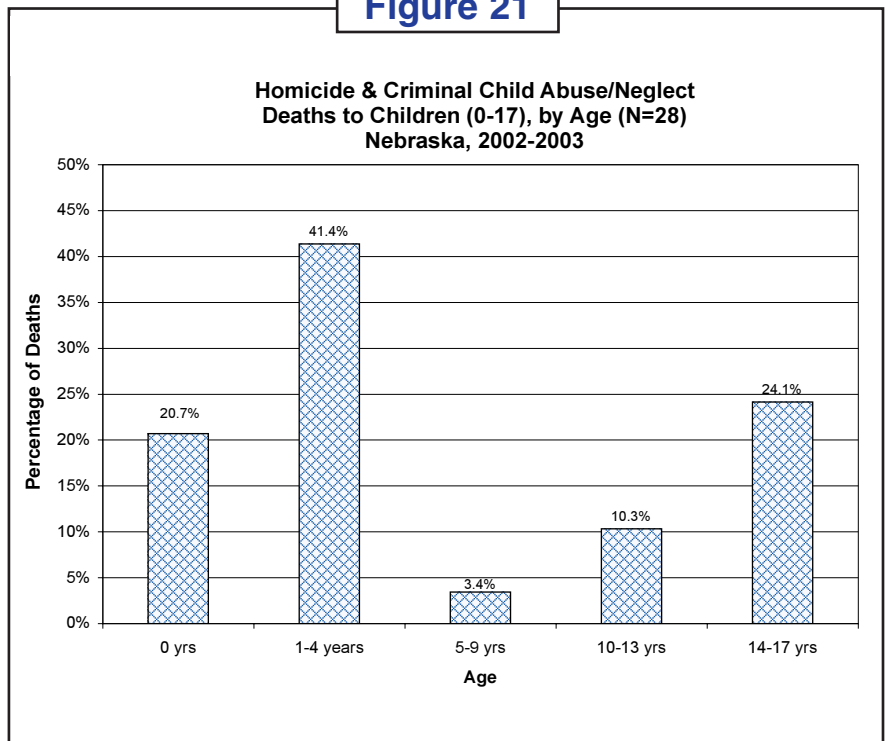
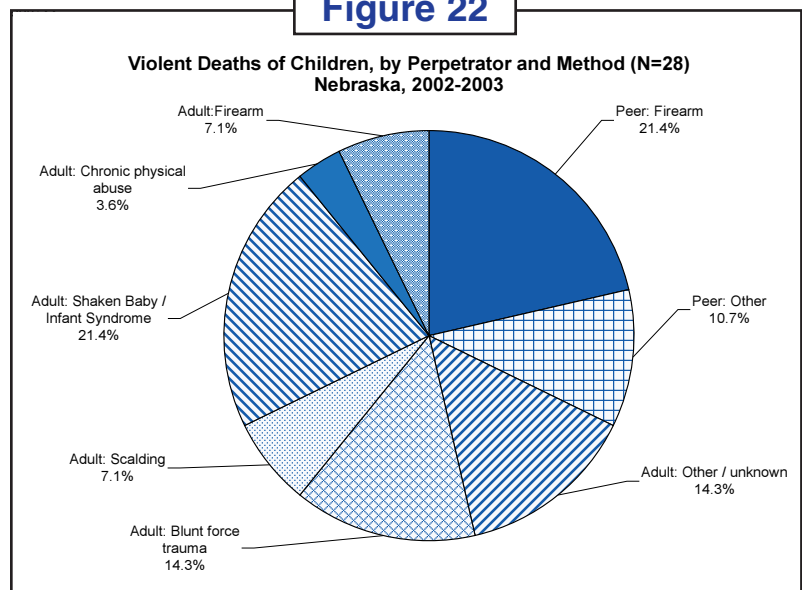


Figure 22



- Exposure to violence, including domestic violence and violent media (e.g., movies, song lyrics, video games);
- Being victimized, including bullying;
- Lack of self-control;
- Low self-efficacy;
- Aggression;
- Gang involvement;
- Substance use; and,
- The availability of guns.

There are multiple resources available to communities wishing to reduce youth violence. At the national level, the Surgeon General's Report on Youth Violence (2001) examines youth violence from a public health perspective, with an important focus on protective factors and effective, research-based prevention strategies that can be implemented by parents, schools, and communities. The Guide to Community Preventive Services reviews the effectiveness of community interventions that work to prevent violence through four main approaches: (1) behavioral change interventions, (2) health and education system level interventions, (3) legislation and public policy interventions, and (4) environmental interventions. Effective community-based programs to prevent youth violence typically include:

- Clear goals and objectives;
- A broad base of community professionals, organizations and parents;
- An understanding of the source of firearms used in crimes; and,
- An understanding of the extent of violence-related injuries as well as deaths.

➤ Recommendations

Communities: *Schools, communities and others concerned about youth violence should be aware of and take advantage of the substantial resources available to help develop effective, community-based prevention programs.*

Support the development of healthy families. To provide for healthy child development, the community must support parents and other adult caretakers of children. Basic support for families includes affordable housing, access to health care, employment, quality day care, quality education, and safe neighborhoods. Specific focus must be directed at teenage parents who are at very high risk of limited parenting skills.

Parents:²⁰

- Monitor/supervise children's use of the Internet, television, reading material, movies, music, and video games.
- Establish and enforce household rules and reward positive behavior.
- Supervise the activities of children; know their schedule and their friends.
- Practice zero-tolerance for bullying in the family and take proactive steps to eliminate bullying in schools.
- Encourage community service.

²⁰ Excerpted from Youth and Violence, Commission for the Prevention of Youth Violence, 2000. Available at <http://www.ama-assn.org/ama/upload/mm/386/fullreport.pdf>.

Discussion – Criminal Child Abuse & Neglect: A sizeable increase in child abuse deaths in Nebraska was noted during 2002 and 2003 (Table 15), prompting the formation of a Governor's Children's Task Force. At the Task Force's request, a CDRT subcommittee reviewed in depth 30 child abuse deaths that occurred between 1998 and 2003. Major findings included that alcohol and drugs play large parts in child neglect, inappropriate child care, child abuse and motor vehicle crashes. Actions taken to prevent child deaths resulting from abuse by a caretaker must include strategies to address the problems of substance abuse and domestic violence.

➤ **Selected Recommendations from the 2003 Governor's Children's Task Force**

Prevention:

- ***Statewide, voluntary home visiting programs are needed that provide support and assistance to expecting and new mothers in their homes.***
- ***There is a need for parent education programs located, for example, in high schools that focus on teen parents, or within substance abuse treatment programs for mothers and families with young children.***

➤ **Recommendations from the Child Death Review Team**

State Policy Makers: Local law enforcement should have the legal and financial ability to require immediate testing for illegal substance use when such use is legitimately suspected to have contributed to the death of a child. It is impossible to assess the involvement of chemical substances in the death of a child if testing for these substances is not done immediately at the death scene on all relevant care providers. Since this is a sensitive issue concerning individual privacy rights, substantial care and sensitivity would need to be exercised so that the constitutional rights of all involved are protected.

Communities and Parents: Expanded availability of safe and affordable child care will reduce the number of children left in inappropriate and/or unsafe situations.

"Never, never, never shake a child®."²¹ Shaking is ineffective in stopping crying and causes tearing and bleeding of veins inside the brain. Severe damage from shaking can occur in children through age five. There are many resources available to help communities understand and publicize the dangers of shaking babies.²²

Never leave a child in the care of someone who is using drugs, especially methamphetamines.

Relatives, friends and neighbors should follow their instincts – and the law - when they suspect substance abuse and/or child abuse/neglect by the caretaker(s) of young children.²³ Public awareness of the signs, symptoms and criteria of abuse and neglect will increase the quality of such reports.

Caretaker Neglect and Inconclusive Neglect - Key Findings

Deaths were attributed to caretaker neglect when a child's caretaker(s) knowingly did something that placed the child's life in danger or did not remove the child from a dangerous situation. The National Center for Child Death Review recognizes five types of supervisory neglect:

²¹ "Never, never, never shake a child" is the copyrighted slogan of SBS Prevention Plus.

²² <http://www.hhs.state.ne.us/protectachild/shakenbaby.htm>.

²³ State law requires any person to report suspected child abuse or neglect to law enforcement, an HHS local office, or the child abuse/neglect reporting number at 1-800-652-1999. All reports are confidential.

- Failure to protect from hazard
- Failure to provide necessities (food, shelter, other)
- Failure to seek medical care / follow treatment
- Emotional neglect
- Abandonment

Deaths where a caretaker was convicted of child abuse or neglect are reported above as Criminal Child Abuse / Neglect. Two child protection specialists from the Team individually reviewed all remaining injury deaths to young children for a possible fit with the categories of neglect listed above. Both reviewers had to agree before categorizing an otherwise “Unintentional Injury” as “Caretaker Neglect.” In all, there were seven cases where the county attorney chose not to prosecute, but where reviewers felt that the death would not have occurred under reasonable standards of supervision or care (Table 16). Five of these cases involved children under five drowning in a bathtub, container or swimming pool, one child was attacked by the family dog and one child became wedged under a reclining chair and suffocated. Two additional cases were left as “Inconclusive,” where reviewers were not comfortable with the unintentional injury classification but did not have sufficient information to clearly determine or rule out neglect (Table 16).

Discussion. Determining when a lack of supervision of small children crosses the line between understandable and negligence is complicated; parental responsibility for supervision is constantly challenged by competing demands. Previous CDRT investigations revealed inconsistency across the state on the types of situations for which caretakers were prosecuted. Nonetheless, reviewers’ intent was to make a reasonable assessment about the amount of time the child was unsupervised and why the caretaker was absent; clearly the younger the child the less time he/she should have been left unwatched and/or unaccounted for.

➤ Recommendations

Policy Makers and Communities: *Expanded access to safe and affordable child care will reduce the number of children left unattended for long periods of time.* Although much of the emphasis in expanding child care opportunities has focused on the importance of nurturing and intellectual stimulation early in a child’s life, safety-related issues should not be overlooked. The business community, policy makers, parents and child care providers working together may be needed to develop locally effective and sustainable solutions.

Parents: *Young children should never be left unsupervised.*

Substance Use During Pregnancy

Nationally, between 5.5% and 18% of all births are thought to be affected by illegal drug use during pregnancy. Established delivery and neonatal complications from illegal drugs such as cocaine and methamphetamine include premature rupture of membranes (PROM), placental abruption, preterm delivery, and pre-eclampsia-like symptoms. However, because these problems also occur in non-drug using women, it is difficult to state with certainty when an infant’s or child’s death was directly related to the mother’s drug use.

As a result, although several child deaths had indications that they were related to gestational exposure to cocaine, other illicit drugs and/or alcohol use, the Team only attributed one death as due to maternal substance use. This infant was born at 23 weeks gestation to a mother with positive toxicology screens at delivery for marijuana and cocaine use, and concurring clinical records.

➤ **Recommendations**

Health Care Providers: *Delivery personnel should be able to recognize and report Fetal Alcohol Syndrome and other disorders related to prenatal alcohol consumption.* The number of maternal alcohol-affected newborns is much likely higher than the zero to five cases reported annually in Nebraska. Accurate knowledge of the prevalence of FAS will aid in its treatment and prevention.

Communities: *Specialized resources should be available for substance-addicted pregnant women who are trying to quit.* Providers need to be aware of available referral options.

Parents and Communities: *Women should abstain from drinking alcohol at any time during pregnancy.* Women are more likely to abstain from drinking during pregnancy when their partner also accepts the need to do so. There is no known safe amount of alcohol to drink while pregnant, nor does there appear to be a safe time to do so.

Medical Error

The Nebraska Medical Association (NMA) performs confidential reviews of neonatal deaths (those that occurred in the first 28 days of life), focusing on the quality of medical care received. While the CDRT data did not indicate any issues, the NMA's more intensive investigation reported three cases where the quality of medical care may have contributed to the death. The NMA has been working with the providers involved to prevent similar problems from reoccurring.

Undetermined

The causes of death of 10 children remained officially undetermined, even after extensive law enforcement and medical investigations (Table 1). Circumstances in these cases were such that neither medical causes nor inflicted injuries could be ruled out. Five of these cases are cross-listed in the SIDS/Sleep-Associated Infant Death section.

No information available

There were no deaths during 2002 and 2003 where the Team was unable to obtain at least minimal cause of death information (Table 1).

UPDATE ON RECOMMENDATIONS FROM PREVIOUS ANNUAL REPORTS

Regarding Pregnancy-Related Deaths

1. (Providers) Continuing education on cause of death determination should be provided to all persons who fill out death certificates. (1996-2001)

Update: The CDRT sponsored a series of statewide workshops in 2005 on accurate determination of cause of death, and how to fill out death certificates. Held in five locations around the state, the well-received workshops were attended by physicians, county attorneys, and coroners. The Team plans to continue this work in 2006.

Regarding SIDS and Infant Suffocation

2. (State Policy Makers) Infants in child care facilities should be put to sleep on their back unless there is a documented medical reason why the child should sleep in a different position. Regulations for child care facilities that require crib “bumper pads” and that allow stuffed toys in cribs should be repealed. (1996-2001)

Update: The Child Care Licensing Program (HHSS) is developing statewide regulations for licensed child care requiring that infants be put to sleep on their backs in the absence of a specific waiver, specifying appropriate sleep surfaces for infants and children, and prohibiting toys and blankets in cribs.

3. (State Policy Makers) State-level funding should support work to reduce the prevalence of smoking among pregnant and postpartum women. (1996-2001)

Update: While there are currently no funded tobacco cessation programs specifically for pregnant and postpartum women, the Tobacco Free Nebraska program currently:

- Distributes the print materials, "Women Kick Butt" to promote smoking cessation;
- Produced a press release for Mothers Day encouraging moms to quit smoking for their own, and their family's health; and,
- Launched a television and radio ad campaign encouraging parents not to smoke in their homes or vehicles. The tag line on the first ad is, "Protect your family. Don't smoke in your home." The tag line on the second ad is, "Protect your children. Don't smoke around them or any child."

4. (State Policy Makers) A standardized death scene investigation should be conducted for all unexpected child deaths. (1996-2001)

Update: Two CDRT members sit on the Child Death Scene Investigation Protocol Committee, a subcommittee of the Governor's Commission for the Protection of Children, convened in 2005 to improve the amount and quality of information obtained after an infant death. LB 1113 (2006) now requires death scene investigations for SIDS deaths, and provides partial funding for autopsies of children under five.

5. (Community Organizations and Child Advocates) Existing SIDS prevention regulations, messages and initiatives should be expanded to include other “Safe Sleeping” issues and options. (1996-2001)

Update: The Nebraska Safe Sleep Initiative (NSSI) was formed in 2005 to reach consensus on key risk reduction messages and to promote safe sleep practices among parents, caregivers, health care providers, and others that influence where and how infants sleep. The AAP SIDS risk reduction policy statement is being used to guide the recommendations. The committee worked with a Douglas County safe sleep initiative

to produce a brochure titled “Nothin’ but Baby! Safe Sleep Tips.”²⁴ Other Douglas County activities include working with child care providers and birthing hospitals on safe sleep practices. The NSSI also sponsored a television and radio ad campaign on safe sleep practices, airing across the state during winter and spring 2006.

Regarding Motor Vehicle Crash Deaths

6. (Parents) A child who has outgrown a child safety seat (generally at 40 pounds) should use a booster seat until approximately age 8 or 80 pounds and/or 4’9” tall.

Update: Effective July 16, 2004, Nebraska’s Child Passenger Restraint Law states, “Children up to age six must ride correctly secured in a federally-approved child safety seat. Children ages six up to age eighteen must ride secured in a safety belt or child safety seat.”

Regarding Child Abuse and Neglect Deaths

7. (State Policy Makers and Communities) Statewide, voluntary home visiting programs are needed that provide support and assistance to expecting and new mothers in their homes. (1996-2001)

Update: LB 425 (2005) appropriated \$200,000 for FY 2006-07 for home visitation programs. Two contractors were selected to work in Douglas and Scottsbluff Counties, beginning December 2006.

8. (Communities and Parents) **“Never, never, never shake a child®.”**²⁵ (1996-2001)

Update:

- The “You Have the Power to Protect a Child” campaign²⁶ was developed by HHSS in response to recommendations made by the Children’s Task Force. The campaign is focusing on raising public awareness on four topics: child abuse prevention, shaken baby syndrome, domestic violence, and substance abuse (specifically methamphetamine); and includes television and radio spots, newspaper ads, and posters and brochures.
 - The Nebraska Child Abuse Prevention Fund Board provides grants to local communities and agencies for child abuse prevention activities. During 2005, NCAPFB awarded over \$170,000 to 11 programs and two community councils for these programs.
9. (State Policy Makers and Communities) Broad-based public education efforts are needed to draw attention to suicide as a significant and preventable cause of death for youth, create awareness of signs that indicate risk for individual youth, and encourage help-seeking actions when at risk youth are identified. (1996-2001)

Update: The Child Death Review Team would like to acknowledge the attention that the Omaha World Herald brought to the problem of youth suicide in Nebraska through a series of articles in 2005.²⁷

²⁴ www.co.douglas.ne.us/dept/health/publications/index.php.

²⁵ “Never, never, never shake a child” is the copyrighted slogan of SBS Prevention Plus.

²⁶ <http://www.hhs.state.ne.us/ProtectAChild/index.htm>

²⁷ http://www.omaha.com/index.php?u_pg=528&u_xid=945&u_sid=1409483.

Glossary

Births

Apgar Score

Newborn viability is most often assessed by the Apgar score. The Apgar score is a widely used assessment of the physical condition of a newborn infant based on heart rate, muscle tone, breathing effort, color and reflex responsiveness. Scores are assessed at 1, 5 and 10 minutes after birth. A score of 10 suggests the healthiest infant, and scores below 5 indicate that the infant needs immediate assistance in adjusting to his or her new environment. The Apgar test is non-invasive and does not involve risk to the newborn.

Birth Defect / Congenital Anomaly

A birth defect is an abnormality of structure, function or metabolism (body chemistry) that is present at birth. Birth defects may be caused by chromosomal or “hereditary” errors or by other influences on the fetus during gestation. They are the leading cause of death for infants. The March of Dimes groups birth defects in three main categories:

- Structural/metabolic (e.g., neural tube defects, missing organs),
- Congenital infections (e.g., Rubella (German measles), syphilis), and
- Other (e.g., Fetal Alcohol Syndrome (FAS)).

For this report, birth defects are only categorized as such if there was no known cause for their occurrence. For example, defects resulting from congenital infections are considered under Maternal Complications; defects resulting from FAS are under Maternal Substance Use.

Gestation

The gestational age of the newborn is the interval between the first day of the mother’s last normal menstrual period (LMP) and the date of birth. It is typically determined by maternal recall, but can also be determined by clinical examination if the mother’s information is not available or is inconsistent with the fetus’ or newborn’s size.

Live Birth

The state of Nebraska defines a live birth as “The complete expulsion or extraction of a product of conception from its mother, irrespective of the period of gestation, which, after such separation, breathes or shows any other evidence of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached, and is reportable.”

Premature birth

Premature birth is a leading cause of infant mortality, yet little is known on how to prevent it. A normal gestation is defined as 37 to 41 weeks; an infant born at 37 or fewer weeks of gestation is considered premature. Through 37 weeks, major systems and organs are still developing. However, babies with at least 28 weeks of gestation are considerably more likely to survive; each additional week of gestation improves the likelihood of survival and decreases the probability of lifelong disabilities. Multiple gestation pregnancies (twins, triplets, etc.) are more likely to deliver prematurely. The prematurity rate is the number of live births of 37 weeks or less gestation divided by the total number of live births.

Viable

Capable of living; born alive and with such form and development of organs as to be capable of living.

Death / Mortality

Cause of Death

The *immediate* cause of death is the disease (condition) or complication occurring closest to the time of death that leads to or contributes to death, and is classifiable according to the International Classification of Diseases (ICD) system. The State of Nebraska used the Ninth Revision for deaths up until 1998, and the Tenth Revision since 1999. However, the immediate cause of death does not necessarily reflect the complete set of reasons for the death. The *underlying* cause of death is the disease or condition that initiated the train of morbid events leading directly to death, and may be many years removed from the actual occurrence of death.

Although immediate causes of death are often preventable, underlying causes are more informative for primary prevention purposes as defined by the Team. For example, pneumonia deaths are largely preventable. However, when pneumonia is the immediate cause of death in a child who is ventilator dependent due to cerebral palsy, prevention of infantile or childhood cerebral palsy becomes the larger, long-term focus. Similarly, while massive head trauma may be an immediate cause of death, prevention of the motor vehicle crash that caused the trauma is as important as improved emergency medical care.

Manner of Death

The manner of death is important and distinct from the cause of death. Manner of death is typically classified as:

- Natural
- Accidental
- Homicide
- Suicide
- Undetermined
- Unknown / No Answer

Fetal Death

The state of Nebraska follows the National Center for Health Statistics' definition of a fetal death as "... death prior to²⁸ the complete expulsion or extraction from its mother of a product of human conception, irrespective of the duration of pregnancy and which is not an induced termination of pregnancy. The death is indicated by the fact that after such expulsion or extraction, the fetus does not breathe or show any other evidence of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles."

Neonatal Death

Death of a live born infant under 28 days of age.

Perinatal Death

Death of a fetus after 28 weeks or more of gestation or of a live born infant within seven days of life.

Medical Conditions

Cancer / Malignant Neoplasms

Cancer begins in cells, the building blocks that make up tissues. Normally, cells grow and divide to form new cells as the body needs them. When cells grow old, they die and new cells take their place. When new cells form

²⁸ Emphasis added.

that the body does not need and old cells do not die when they should, these extra cells can form a mass of tissue called a growth or tumor. Not all tumors are cancer. Tumors can be benign or malignant:

- Benign tumors are not cancer
 - Benign tumors are rarely life-threatening.
 - Usually, benign tumors can be removed, and they seldom grow back.
 - Cells from benign tumors do not spread to tissues around them or to other parts of the body.
- Malignant tumors are cancer
 - Malignant tumors generally are more serious than benign tumors. They may be life-threatening.
 - Malignant tumors often can be removed, but they can grow back.

Hypoxia / Asphyxia

Hypoxia is an insufficient supply of oxygen to the brain. The American Academy of Pediatrics states that an infant who has had "asphyxia" or hypoxia immediately prior to or during delivery that is severe enough to result in acute neurologic injury should demonstrate all of the following: (a) profound metabolic or mixed acidemia (ph <7.00) on an umbilical arterial blood sample, if obtained, (b) an Apgar score of 0 to 3 for longer than 5 minutes, (c) neurologic manifestation, e.g., Seizure, coma, or hypotonia, and (d) evidence of multiorgan dysfunction. Because this level of detail was rarely available for this report, the physician's or pathologist's assessment was accepted.

Neural tube defect(s)

The neural tube is the part of the developing fetus that becomes the spinal cord and brain. Neural tubes close within the first four weeks of gestation, often before a woman knows she is pregnant; neural tube defects (NTD) occur when the tube only closes partially or not at all. NTDs are among the most common of all serious birth defects.

The two major types of NTDs are anencephaly and spina bifida. Anencephaly is the partial or complete absence of the baby's brain. This defect causes extensive damage, and most of these babies are stillborn or die soon after birth. Spina bifida occurs when an opening remains in the spine. These babies need surgery soon after birth to close the spine and prevent further damage. They also may need a shunt or a drain to prevent a build-up of spinal fluid in the brain called hydrocephalus. Babies with spina bifida may lack feeling in their legs and later develop problems with walking. In addition, these children may develop problems with their bowel and bladder control. They may also have learning problems, and some have mental retardation.

Sudden Infant Death Syndrome (SIDS)

SIDS is officially defined as the sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history. In Nebraska, only the autopsy is required.²⁹ Major risk factors for SIDS are pre- or post-natal exposure to tobacco smoke, low birth weight, not breast-feeding, and the baby not sleeping on his/her back. SIDS is officially a diagnosis of exclusion, when no legitimate cause of death can be determined by autopsy or other means.

Trisomy

Trisomies are genetic conditions present at birth where cells contain three copies of specific chromosomes instead of the normal two copies. For example, the presence of three copies of chromosome 21 is called Trisomy 21. A partial trisomy occurs when part of an extra chromosome is attached to one of the other chromosomes. A mosaic trisomy occurs when not all cells contain the extra chromosomal material. Trisomies can result in birth defects, miscarriage or early infant death.

²⁹ Nebr. Rev. Stat. §71-605.

Other Terms

Preventability

The Team focuses on identifying deaths that could have been prevented under Nebraska's definition:

"Preventable child death shall mean the death of any child which reasonable medical, social, legal, psychological, or educational intervention may have prevented. Preventable child death shall include, but not be limited to, the death of a child from (a) intentional and unintentional injuries, (b) medical misadventures, including untoward results, malpractice, and foreseeable complications, (c) lack of access to medical care, (d) neglect and reckless conduct, including failure to supervise and failure to seek medical care for various reasons, and (e) preventable premature birth; Reasonable shall mean taking into consideration the condition, circumstances, and resources available." §71-3405 Neb. Rev. Stat.

While preventability is often a straightforward assessment, it can also be quite challenging. For example, if a seizure disorder has been controlled with medications yet causes a 17-year old driver to have a fatal motor vehicle crash, preventability becomes problematic. Because of the large number of cases reviewed for this report, individual assessments of preventability were made only for potential "Caretaker Neglect." Team members did feel that it is reasonable to assume that most motor vehicle-related deaths are preventable, particularly given the large numbers of deaths that occurred when an unrestrained child was ejected from the vehicle. Likewise, the unintentional and intentional injuries were largely preventable. On the other hand, most of the medical conditions appeared to have received appropriate medical care and thus the resulting deaths were perhaps not preventable.

Although the Team is comfortable with the generalized assessments of preventability made for this report, it is clear that determinations made on a case by case basis are preferable. This is the process that will be followed for subsequent years' reports.

Race and Ethnicity

Nebraska assigns infant race and ethnicity at birth as that of the mother as reported on the birth certificate. Ethnicity and race are overlapping categories and are thus reported separately. For the time period of these data (2002-2003), Nebraska recognized four racial categories: White, African-American, Native American and Asian / Pacific Islander.

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Appendix – Detailed Data Tables

Table 1.

Underlying Cause of Death	1996 (N)	1997 (N)	1998 (N)	1999 (N)	2000 (N)	2001 (N)	1996-2001 Total	2002 (N)	2003 (N)	2002-2003 Total
Preterm Birth	43	51	40	39	47	34	254	44	24	68
Maternal Complications	41	24	34	29	38	46	212	35	34	69
Complications of Labor & Delivery	13	9	5	9	4	5	45	7	1	8
Other Pregnancy & Neonatal-Related Conditions	5	9	6	4	1	5	30	0	0	0
Total, Pregnancy-Related	102	93	85	81	90	90	541	86	59	145
Pregnancy Related	102	93	85	81	90	90	541	86	59	145
Birth Defects / Inherited & Chromosomal Disorders	73	56	57	59	66	69	380	68	61	129
SIDS	35	23	25	24	27	26	160	19	23	42
Cancer / Neoplasms	14	9	11	11	11	8	64	12	9	21
Infectious, Chronic & Other Medical Conditions	24	17	26	29	20	22	138	27	17	44
Motor Vehicle Crash	52	43	43	47	36	38	259	44	48	92
Non-MVC Unintentional Injuries	15	17	17	19	19	11	98	17	15	32
Suicide	14	13	10	13	11	9	70	12	10	22
Homicide / Criminal Child Abuse & Neglect	11	14	9	8	14	7	63	13	15	28
Caretaker Neglect	4	3	5	8	6	3	29	4	3	7
Inconclusive Neglect	0	5	2	0	0	1	8	0	2	2
Maternal Substance Use	0	0	0	2	0	2	4	1	0	1
Medical Error	0	0	0	1	0	0	1	0	0	0
Undetermined	1	1	0	1	1	2	6	5	5	10
No Information Available	12	2	10	0	0	0	24	0	0	0
Total (N)	357	296	300	303	301	288	1,845	308	267	575

Underlying Cause of Death	1996 (%)	1997 (%)	1998 (%)	1999 (%)	2000 (%)	2001 (%)	1996-2001 Total	2002 (%)	2003 (%)	2002-2003 Total
Preterm Birth	42.2%	54.8%	47.1%	48.1%	52.2%	37.8%	47.0%	51.2%	40.7%	46.9%
Maternal Complications	40.2%	25.8%	40%	35.8%	42.2%	51.1%	39.2%	40.7%	57.6%	47.6%
Complications of Labor & Delivery	12.7%	9.7%	5.9%	11.1%	4.4%	5.6%	8.3%	8.1%	1.7%	5.5%
Other Pregnancy & Neonatal-Related Conditions	4.9%	9.7%	7.1%	4.9%	1.1%	5.6%	5.5%	0%	0%	0%
Total, Pregnancy-Related	100.00 %	100.00 %	100.10 %	99.90%	99.90%	100.10 %	100.0%	100.0%	100.0%	100.0%
Pregnancy Related	28.6%	31.4%	28.3%	26.7%	29.9%	31.3%	29.4%	27.9%	22.1%	25.2%
Birth Defects / Inherited & Chromosomal Disorders	20.4%	18.9%	19.0%	19.5%	21.9%	24.0%	20.6%	22.1%	22.8%	22.4%
SIDS	9.8%	7.8%	8.3%	7.9%	9.0%	9.0%	8.6%	6.2%	8.6%	7.3%
Cancer / Neoplasms	3.9%	3.0%	3.7%	3.6%	3.7%	2.8%	3.4%	3.9%	3.4%	3.7%
Infectious, Chronic & Other Medical Conditions	6.7%	5.7%	8.7%	9.6%	6.6%	7.6%	7.5%	8.8%	6.4%	7.7%
Motor Vehicle Crash	14.6%	14.5%	14.3%	15.5%	12.0%	13.2%	14.0%	14.3%	18.0%	16.0%
Non-MVC Unintentional Injuries	4.2%	5.7%	5.7%	6.3%	6.3%	3.8%	5.3%	5.5%	5.6%	5.6%
Suicide	3.9%	4.4%	3.3%	4.3%	3.7%	3.1%	3.8%	3.9%	3.7%	3.8%
Homicide / Criminal Child Abuse & Neglect	3.1%	4.7%	3.0%	2.6%	4.7%	2.4%	3.4%	4.2%	5.6%	4.9%
Caretaker Neglect	1.1%	1.0%	1.7%	2.6%	2.0%	1.0%	1.6%	1.3%	1.1%	1.2%
Inconclusive Neglect	0%	1.7%	0.7%	0%	0%	0.3%	0.5%	0%	0.7%	0.3%
Maternal Substance Use	0%	0%	0%	0.7%	0%	0.7%	0.2%	0.3%	0%	0.2%
Medical Error	0%	0%	0%	0.3%	0%	0%	0.1%	0%	0%	0%
Undetermined	0.3%	0.3%	0%	0.3%	0.3%	0.7%	0.3%	1.6%	1.9%	1.7%
No Information Available	3.4%	0.7%	3.3%	0%	0%	0%	1.2%	0%	0%	0%
Total (N)	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100%

Table 2.

Preterm Births	1996 (N)	1997 (N)	1998 (N)	1999 (N)	2000 (N)	2001 (N)	1996-2001 Total	2002 (N)	2003 (N)	2002-2003 Total
Singleton gestation	25	31	27	26	22	20	151 (59.4%)	23	14	37 (54.4%)
Multiple gestation	18	20	13	13	25	14	103 (40.6%)	21	10	31 (45.6%)
Total (N)	43	51	40	39	47	34	254	44	24	68

Table 3.

Maternal Complications	1996 (N)	1997 (N)	1998 (N)	1999 (N)	2000 (N)	2001 (N)	1996-2001 Total	2002 (N)	2003 (N)	2002-2003 Total
Diabetes, gestational	1				1	2	4 (1.9%)		1	1 (1.4%)
HELLP syndrome			5 ¹			1	6 (2.8%)		1	1 (1.4%)
Hypertension, pregnancy-induced or chronic		2	4	1		1	8 (3.8%)		2	2 (2.9%)
Incompetent cervix	7	6	14	6	12	10	55 (25.9%)	7	9	16 (23.2%)
Infection / chorioamnionitis	3	1	2	2	5	6	19 (9.0%)	4	6	10 (14.5%)
Infection, cytomegalovirus	1	1			2	2	6 (2.8%)	1		1 (1.4%)
Infection, Group B Streptococcus							0	1		1 (1.4%)
Infection, herpes virus	1		1	1			3 (1.4%)			0
Infection, HIV	1						1 (0.5%)			0
Infection, other							0	1	1	2 (2.9%)
Placental abruption / separation	10	3	4	13	11	9	50 (23.6%)	9	5	14 (20.3%)
Placenta previa		1		1	1	4	7 (3.3%)	3	1	4 (5.8%)
Pre-eclampsia / eclampsia	4	2		2	2	3	13 (6.1%)	4	2	6 (8.7%)
Vaginal bleeding / uterine rupture	9	3	1	2	1	4	20 (9.4%)	1	3	4 (5.8%)
Other / unknown	2	4	3	1	3	3	16 (7.5%)	4	3	7 (10.1%)
Total (N)	41	24	34	29	38	46	212	35	34	69

¹Includes one set of triplets.

Table 4.

Complications of Labor & Delivery	1996 (N)	1997 (N)	1998 (N)	1999 (N)	2000 (N)	2001 (N)	1996-2001 Total	2002 (N)	2003 (N)	2002-2003 Total
Aspiration pneumonia							0	1		1 (12.5%)
Delivery trauma				1	2	1	4 (8.9%)	1		1 (12.5%)
Meconium aspiration	2	1		3		1	7 (15.6%)	1	1	2 (25.0%)
Perinatal hypoxia / asphyxia	11	8	5	5	2	3	34 (75.6%)	4		4 (50.0%)
Total (N)	13	9	5	9	4	5	45	7	1	8

¹ Includes one set of triplets.

Table 5.

Birth Defects / Inherited & Chromosomal Disorders ²	1996	1997	1998	1999	2000	2001	1996-2001 Total	2002	2003	2002-2003 Total
Neonatal (< 1 day)	(N)	(N)	(N)	(N)	(N)	(N)	(N)	(N)	(N)	(N)
Bone disorder		2	1	1	1	1	6	1	1	2
Chromosomal anomaly, Trisomy 13 (Patau syndrome)	2	1				1	4	1	2	3
Chromosomal anomaly, Trisomy 18 (Edwards syndrome)			3	1	1		5	1		1
Chromosomal anomaly, Trisomy 21 (Down syndrome)					1		1	1		1
Chromosomal anomaly, other	1		1	3	1	1	7	2		2
Conjoined twins							0		2	2
DiGeorge syndrome							0	1		1
Diaphragmatic hernia							0	2	1	3
Gastrointestinal / genitourinary anomaly	2		1		1	4	8			
Head / brain anomaly		1			2	1	4		1	1
Heart defect / anomaly	1	2	1	1		1	6		5	5
Hydrops fetalis, non-immune				1			1	1	2	3
Kidney defect / anomaly	4	7	3	4	1	2	21	7	2	9
Liver defect / anomaly		1					1			0
Lung defect / anomaly				1		2	3			0
Mickel-Gruber Syndrome				1			1			0
Morquio's Syndrome		1					1			0
Multiple congenital anomalies	1	1	3	2	5	5	17	2	1	3
Neural tube defect - anencephaly	5	2	3	3			13	6	3	9
Neural tube defect - encephalocele	1		1				2			0
Neural tube defect - myelomeningocele / spina bifida	1				1		2	1		1
Turner's syndrome				1			1			0
Subtotal (N)	18 (24.7%)	18 (32.1%)	17 (29.8%)	19 (32.2%)	14 (21.2%)	18 (26.1%)	104 (27.4%)	26 (38.2%)	20 (32.8%)	46 (35.7%)
Post-neonatal (1+ days)	Age	Age	Age	Age	Age	Age	(N)	Age	Age	(N)
Anemia, Fanconi's						5y	1			0
Anemia, sickle cell							0		1y	1
Alstrom syndrome							0		13y	1
Anemia, sickle cell					13y		1			0
Batten's disease				7y, 8y ³			2			0
Bone disorders	4d	8d	2m, 10m	1d			5		2d, 1y	2
Bowen Conradi syndrome	10y						1			0
Central Nervous System disorders	6wks, 9y					7y	3			0
Cerebro-costo-mandibular Syndrome	4y						1			0
Chromosomal anomaly, Trisomy 13 (Patau syndrome)	1d, 3d			2d	2d, 3d, 4d, 5d,		7	2d	4d, 4d, 6d	4
Chromosomal anomaly, Trisomy 18 (Edwards syndrome)	1d, 3d, 4d, 1m, 2m	1d, 1m, 2m	2d, 7d	2d, 4d, 4d	1d, 5d, 2m, 4m, 8m, 1y	1d, 5d, 22d, 1m, 7m	24	3d, 5d, 11d, 15d	1d, 5d	6

² For birth defect-related deaths under one day old, the number of cases are given. For deaths greater than one day, ages are given in years (y), months (m) and days (d).

³ Siblings.

Table 5. (continued)

Chromosomal anomaly, Trisomy 21 (Down syndrome)	3m, 6m	3y	3m, 2y	15y	8m	6y	8	11y	1y	2
Chromosomal anomaly, other	6d	1m		16d, 14y		2y, 3y	6	1y, 11y	2y	3
Cockayne syndrome							0	5y		1
Coffin-Siris Syndrome					11y		1			0
Costello's Syndrome			6m				1			0
Cystic fibrosis				17y			1			0
Dandy Walker Syndrome			2y		9m		2			0
DiGeorge syndrome			26d	4y	11m	1y	4		2m	1
Gastrointestinal / genitourinary malformations, diaphragmatic hernia							0	15d	12d, 1m	3
Gastrointestinal / genitourinary malformations, other ⁴	1d, 18d, 1y, 2y	17d	2d, 15d, 2m, 5m	1d, 3y	1d, 1m, 7y	4y, 14y	16			0
Head / brain anomalies, encephalopathy		6m					1	1m		1
Head / brain anomalies, hydrocephaly	3m, 12y, 16y	10y, 14y					5		14y	1
Head / brain anomalies, other	6y	2y		14y	2d, 7m, 2y, 7y, 9y	11m, 1y, 2y	11	1m	8d, 10d	3
Heart disease, hypoplastic left	1d, 7d, 8d, 14d, 1m	2d, 8d, 11d, 1wk, 1y, 2y	2d, 6d, 5m	10d, 2m, 4m, 7m,	1d, 9d, 10d, 1m, 2m	3d, 2m, 3m	26	2d, 20d, 3m	3d, 23d, 6m, 1y	7
Heart disease, other	2d, 25d, 3m, 5m, 11m, 1y, 2y, 16y	2d, 5d, 6m, 12y, 16y	5d, 7d, 10d, 15d, 21d, 1m, 1m, 3m, 4m, 5m, 5m, 2y	1d, 2d, 2d, 3d, 1m, 2m, 5m, 8m, 2y, 9y, 9y	5d, 5d, 6d, 15d, 1m, 2m, 5m, 9m, 1y, 6y	1d, 7d, 8d, 8d, 13d, 16d, 16d, 1m, 1m, 1m, 4m, 8m, 9y, 12y	61	3d, 3d, 8d, 8d, 15d, 19d, 24d, 30d, 1m, 1m, 2m, 5m, 9m, 2y, 8y	17d, 2w, 2m, 6m, 1y, 1y	21
Hemachromatosis					14y		1			0
Hurler's Syndrome	1y				5y		2			0
Hydromyelia			4m				1			0
Hydrops, non-immune			2d		5d	1m	3	2d		1
Hystiocytosis X		1y					1	4y		1
Intestinal malrotation							0		1d	1
Kidney defect / anomaly		1d, 3d		1d		15y	4	2m	1m	2
Klippel-Trenaunay-Weber syndrome							0		14y	1
Leukemia, congenital							0		11d	1
Leukodystrophy, metachromatic							0	16y		1
Liver defect / anomaly							0	10y	2y	2
Menke's Disease		2y					1	9m		1
Metabolic disorder	7d	6m	10m			2d, 3m	5			0
Microvillus inclusion disease							0	2y		1
Multiple congenital anomalies	5d, 12d, 1m, 2y, 3y, 5y	1d, 6d, 9d, 28d, 3m, 5m, 7m, 7m	12d, 25d, 10y	17d, 2m, 4m, 8m, 9m	3m, 2y	3d, 5y, 5y, 17y	28	1y	2d, 3d, 5y	4
Muscular dystrophy	15y			17y		17y	3			0
Myotonia, congenital	1m						1			0
Myotonic dystrophy						16y	1			0
Neural tube defect, anencephaly			1d		1d, 1d, 2d, 3d, 5d		6		1m	1
Neural tube defect, encephalocele				4m		3d	2			0

⁴ Includes diaphragmatic hernia between 1996 and 2001.

Table 5. (continued)

Neural tube defect, myelomeningocele / spina bifida	9d, 21d	7y	13y		14y		5	5y	12y, 13y	3
Neuromuscular disorder	28d, 5m, 6y				2m, 4m	19d, 6m, 1y	8			0
Otahara syndrome			9m				1	6y		1
Pena Shokeir Syndrome	16d						1			0
Persistent pulmonary hypertension	5m						1			0
Rett syndrome							0		1y	1
Sandhoff Disease							0		3y	1
Seizure disorder				9y			1			0
Smith-Lemli-Opitz syndrome (defective cholesterol synthesis)							0	11d		1
Spinal muscle atrophy, infantile form (Verdnic Hoffman disease)							0		2m	1
Tay-Sach's Disease		3y					1			0
Tracheal stenosis			1y				1			0
Tumor, neuroectodermal							0	6m		1
Zellweger's Syndrome		2m	3d				2			0
Subtotal (N)	55 (75.3%)	38 (67.9%)	40 (70.2%)	40 (67.8%)	52 (78.8%)	51 (73.9%)	276 (72.6%)	42 (61.8%)	41 (67.2%)	83 (64.3%)
Total (N)	73	56	57	59	66	69	380	68	61	129

Table 6.

Sleep-Associated Death – Race / Ethnicity	2002			2003			Total		
	SIDS	Other Diagnoses	Subtotal	SIDS	Other Diagnoses	Subtotal	SIDS	Other Diagnoses	Total
White	14	4	18	15	1	16	29 (69.0%)	5 (50.0%)	34 (65.4%)
African-American	2	2	4	5	0	5	7 (16.7%)	2 (20.0%)	9 (17.3%)
Native American	2	1	3	3	2	5	5 (11.9%)	3 (30.0%)	8 (15.4%)
Asian	1	0	1	0	0	0	1 (2.4%)	0	1 (1.9%)
Total (N)	19 (73.1%)	7 (26.9%)	26	23 (88.5%)	3 (11.5%)	26	42 (80.8%)	10 (19.2%)	52
Hispanic Ethnicity	5	0	5	3	1	4	8 (19.0%)	1 (10.0%)	9 (17.3%)

Table 7.

Sleep-Associated Death – Sex	2002			2003			Total		
	SIDS	Other Diagnoses	Subtotal	SIDS	Other Diagnoses	Subtotal	SIDS	Other Diagnoses	Total
Male	13	5	18	11	2	13	24 (57.1%)	7 (70.0%)	31 (59.6%)
Female	6	2	8	12	1	13	18 (42.9%)	3 (30.0%)	21 (40.4%)
Total (N)	19 (73.1%)	7 (26.9%)	26	23 (88.5%)	3 (11.5%)	26	42 (80.8%)	10 (19.2%)	52

Table 8.

Sleep-Associated Death – Caretaker	2002			2003			Total		
	SIDS	Other Diagnoses	Subtotal	SIDS	Other Diagnoses	Subtotal	SIDS	Other Diagnoses	Total
Babysitter / Child Care	4	2	6	2	0	2	6 (14.3%)	2 (20.0%)	8 (15.4%)
Parents / Family member	14	5	19	21	2	23	35 (83.3%)	7 (70.0%)	42 (80.8%)
Unknown	1	0	1	0	1	1	1 (2.4%)	1 (10.0%)	2 (3.8%)
Total (N)	19 (73.1%)	7 (26.9%)	26	23 (88.5%)	3 (11.5%)	26	42 (80.8%)	10 (19.2%)	52

Table 9.

Sleep-Associated Death – Risk Factors	Official Cause of Death (2002-2003)				Total
	SIDS	Suffocation	Pneumonia / Bronchiolitis	Undetermined	
Pre- or post-natal smoke exposure	26 (61.9%)	1 (100.0%)	2 (50.0%)	3 (60.0%)	32 (61.5%)
Current / recent respiratory infection	24 (57.1%)	1 (100.0%)	3 (75.0%)	0	28 (53.8%)
Age-inappropriate sleep surface	22 (52.4%)	0	2 (50.0%)	4 (80.0%)	28 (53.8%)
Bed-sharing	18 (42.9%)	0	1 (25.0%)	3 (60.0%)	22 (42.3%)
Bedding-related issues	15 (35.7%)	1 (100.0%)	1 (25.0%)	1 (20.0%)	18 (34.6%)
Side or stomach sleeping	16 (38.1%)	0	0	1 (20.0%)	17 (32.7%)
Furniture-related issues	1 (2.4%)	1 (100.0%)	0	0	2 (3.8%)
No known risk factors	2 (4.8%)	0	0	0	2 (3.8%)
Total	42 (80.8%)	1 (1.9%)	4 (7.7%)	5 (9.6%)	52

Table 10.

Cancer / Neoplasms	1996 (Age)	1997 (Age)	1998 (Age)	1999 (Age)	2000 (Age)	2001 (Age)	1996-2001 Total	2002 (Age)	2003 (Age)	2002-2003 Total
Adrenal gland tumor								9y	5y	2
Astrocytoma / glioma	3y, 7y		5y, 8y, 11y, 13y	8y, 17		15y	9	3y, 5y, 16y	7y	4
Blastoma, unspecified			2y				1			0
Bone tumor					10y		1			0
Brain tumor								4y, 9y, 10y	2y	4
Ependymoma	11y, 11y						2			0
Ependymoma vs. astrocytoma				13y			1			0
Hepatic blastoma / carcinoma		6y					1		5y	1
Leukemia, acute or chronic	8y	1y	6m	1y, 2y, 15y, 17	3y, 12y, 12y	13y, 16y	12			0
Lymphoma, Hodgkin's						17y	1		17y	1
Lymphoma, non-Hodgkin's ("lymphoblastic")			12y				1	11y		1
Medulloblastoma		15y		5y			2		8y	1
Mesothelioma, peritoneal						17y	1			0
Neuroblastoma		5y	3y, 9y	10y	3y, 4y, 4y		7	5y		1
Neuroendocrine tumor	11y						1			0
Osteosarcoma							0		4y	1
Palate tumor							0		16y	1
Pelvic sarcoma							0	14y		1
Pineal gland dysgerminoma	9y						1			0
Renal medullary carcinoma	11y						1			0
Rhabdoid tumor of the kidney		1y		11m			2			0
Rhabdomyosarcoma	17y, 17y		6y		7y		4			0
Wilms' tumor							0	3y, 6y	16y	3
Unspecified type	17y						1			0
Total (N)	14	9	11	11	11	8	64	12	9	21

Ages are given in years (y) and months (m).

Table 11.

Infectious, Chronic and Other Disease Conditions	1996 (Age)	1997 (Age)	1998 (Age)	1999 (Age)	2000 (Age)	2001 (Age)	1996-2001 Total	2002 (Age)	2003 (Age)	2002-2003 Total
Anemia, aplastic					11y		1			0
Appendix, perforated/ruptured			13y		12y		2			0
Asthma, treated	9y, 13y, 17y	11y, 14y		7y, 10y, 13y, 14y, 17y	16y, 15y	14y	13	17y		1
Asthma, untreated							0		9y	1
Asthma, unknown treatment	10y, 14y	15y					3			0
Bronchitis / bronchiolitis/ bronchopneumonia ⁵	4m		1y	7m, 7m, 3y		1m, 5y, 14y,	8	28d, 2m, 4m, 8m, 1y, 2y, 8y	2m	8
Cerebral palsy (complications)		5y, 8y, 10y, 10y	1y, 3y, 5y, 8y, 15y, 16y	3y, 5y, 11y	15y, 16y	4y, 5y, 17y	18	8y, 15y, 15y, 15y	9y, 17y	6
Cerebral aneurysm							0		4m	1
Chickenpox		9y					1			0
Complications of surgery							0		2y, 12y	2
Cystic fibrosis			16y		13y		2			0
Dermatomyositis				13y			1			0
Diabetes mellitus ⁶					1y	2y	2			0
Drug abuse (crank), chronic	17y						1			0
Encephalitis / encephalopathy		15y		15y		1y	3			0
Epilepsy					1y, 7y		2			0
Evans Syndrome / moyamoya disease							0	9y		1
Gastroenteritis							0	1y		1
Gastroesophageal reflux disease							0		15y	1
Glomerulonephritis						11y	1			0
Heart disease, cardiomegaly							0	14y	13y	2
Heart disease, myocarditis		3m	18m	11m	5y	2y	5		13y	1
Heart disease, other ⁷	13y, 17y	2y, 13y, 15y, 17y	16y	2y, 15y		2y, 12y	11			0
Hemolytic uremic syndrome					2y		1		1y	1
Hemorrhage, subarachnoid				17y			1			0
Hepatitis C				17y			1			0
Hypothyroidism / seizure disorder							0	11y		1
Idiopathic inclusion body myopathy	3m						1			0
Infantile spasm/seizure disorder							0	6m, 3y		2
Intestinal disorders, vascular							0	1m		1
Laryngeal tracheitis				2y		3y	2			0
Leukodystrophy, adrenal			12y				1			0
Liver failure / probable fatal infectious mononucleosis	14y						1			0
Liver failure, unknown cause	16y		3m				2	2y		1
Lung disease, unspecified			2y				1			0
Lymphoma, non-Hodgkins	16y						1			0
Meckel's diverticulum, perforation of				3y			1			0

⁵ Three of these deaths are also cross-listed in the sleep-related infant death section.

⁶ An additional diabetes-related death is included in the "Supervisory / Caretaker Neglect" category.

⁷ Predominantly cardiomyopathy; cardiomegaly; arteriosclerotic heart disease; atherosclerotic heart disease.

Table 11. (continued)

Meningitis, Group B streptococcal							0	1m	8m	2
Meningitis, type not specified	1y	13d	12w, 1y		20d	6y	6			0
Mononucleosis	14y						1			0
Motor neuron disease						15y	1			0
Pneumonia, aspiration	3y, 11y					3y	3			0
Pneumonia, MRSA							0		6m	1
Pneumonia, H. influenza + S. pneumonia							0	1m		1
Pneumonia / pneumonitis ⁸	7m, 14y		2m, 12y		1m, 2m, 3m	12y	8			0
Probable metabolic disorder							0	5m		1
Pulmonary fibrosis, idiopathic							0	13y		1
Pulmonary hypertension, primary							0		16y	1
Reflux disease		3m	3m				2			0
Respiratory Syncytial Virus (RSV)			7y	6m, 6m, 4y			4	2m, 3m		2
Reye's Syndrome			10y				1			0
Seizure disorder	8m, 12y	11y		7y			4			0
Sepsis, bacterial / viral ⁹	2y			5m, 10m, 2y		12d, 4y	6		6d, 1m, 5y	3
Stevens-Johnson Disease				2y			1			0
Streptococcal arthritis, complications from						12y	1			0
Tonsillectomy, post-surgical complications	17y						1			0
Waterhouse-Friderichsen syndrome					1y		1			0
Other	1d		3m, 11y	5y	12y	17y	6			0
Undetermined medical cause			14d, 5y, 15y		1y, 15y		5	13y		1
TOTAL	24	17	26	29	20	22	138	27	17	44

Ages are given in years (y), months (m) and days (d).

⁸ Streptococcal and unspecified.

⁹ Pneumococcal, streptococcal, enteroviral, rotaviral, and unspecified.

Table 12.

Motor Vehicle-Related Incidents	1996 (N)	1997 (N)	1998 (N)	1999 (N)	2000 (N)	2001 (N)	1996-2001 Total	2002 (N)	2003 (N)	2002-2003 Total
Motor Vehicle Crash - Restraint status¹⁰										
Restrained	8	3	3	3	4	3	24 (11.0%)	9	6	15 (19.5%)
Not restrained	14	5	9	6	5	2	41 (18.8%)	14	9	23 (29.9%)
Ejected	4	10	8	12	9	7	50 (22.9%)	15	14	29 (37.7%)
Unknown	15	21	14	21	16	16	103 (47.2%)	3	7	10 (13.0%)
MVC Subtotal	41	39	34	42	34	28	218 (84.2%)	41	36	77 (83.7%)
Pedestrian	7	2	4	2	1	3	19 (7.3%)	1	3	4 (4.3%)
Bicycle	2	1	4	1		3	11 (4.2%)	2	1	3 (3.3%)
Vehicle fire							0		5	5 (5.4%)
All-terrain vehicle							0		2	2 (2.2%)
Train-car							0		1	1 (1.1%)
Motorcycle		1		1			2 (0.8%)			0
Other	2		1	1	1	4 ¹¹	9 (3.5%)			0
Total	52	43	43	47	36	38	259	44	48	92

¹⁰ Age-appropriate restraints: carseat or booster seat for children through age eight; seatbelt and/or shoulder harness for older ages.

¹¹ Three deaths occurred in one school bus accident.

Table 13.

Unintentional Injury ¹²	1996 (Age)	1997 (Age)	1998 (Age)	1999 (Age)	2000 (Age)	2001 (Age)	1996-2001 Total	2002 (Age)	2003 (Age)	2002-2003 Total
Athletic injury							0		12y	1
Animal-drawn vehicle ¹³						9	1			0
Bitten by dogs							0		3y	1
Carbon monoxide poisoning			17				1			0
Choked on food		2	1	3	11	4	5	1y		1
Crushed under falling object				3, 17			2			0
Drowned, ¹⁴ bath tub	2						1			0
Drowned, toilet							0	1y		1
Drowned, farm tank/trough							0	1y, 1y		2
Drowned, pool / unknown ¹⁵		13	1		17	13	4	3y		1
Drowned, open water (swimming / canoeing / body surfing / wading / rescue attempt)	11, 17, 17	17, 17	14	11, 16	12, 16, 17, 17		12	14y	7y, 13y	3
Electrocution, playing around power lines	7		11	14			3			0
Explosion, building pipe bombs					17		1			0
Fall from and stepped on by horse	2	12	10				3	5y		1
Fall in grain elevator							0		13y	1
Fall, other		8	14				2	6y		1
Fight				15			1			0
Fire, house/trailer/apartment							0	10y	10y & 13y, 5y	4
Hit by jet ski							0	17y		1
Hit by object falling from truck							0		13y	1
Hit by object, other	13	10		5, 15	16		5			0
Hit / crushed by moving vehicle in driveway, not in traffic		2	5, 16		5, 16		5	1y, 2y, 3y	1y, 2y	5
Hit / run over by farm or construction vehicle, not in traffic		3, 3		13	5	5, 16	6			0
Hypothermia (cold), outdoor exposure		17					1			0
Knife wound	12			12			2			0
Methamphetamine intoxication							0	15y		1
Overdose, over-the-counter or prescription medication		17			16	17	3			0
Playing with firearm	13, 14	15	16				4		9y	1
Poisoning, unintentional							0		15y	1
Suffocation, crib / bed parts	1		1, 1, 9	5m, 4m	7m		7			0
Suffocation, other unintentional				6, 15, 17			3			0
Suffocation, overlay	1m	3wks			1m, 3m		4			0
Suffocation, placed faced down in crib	1m				1m		2			0

¹² One infant suffocation death is cross-listed in the SIDS/SUID section.

¹³ Incident occurred out-of-state; no details available.

¹⁴ Includes near-drowning, where child was resuscitated but later died from effects of oxygen deprivation.

¹⁵ All unknowns were between 1996 and 2001.

Table 13. (continued)

Suffocation / strangulation, unintentional							0	13y, 13y	5m, 1y	4
Wasp sting (allergic reaction)							0	1y		1
Total (N)	13	14	13	16	16	6	78	17	15	32

Ages are given in years (y), months (m) and weeks (wks).

Table 14.

Suicide		Firearms (Age)	Hanging (Age)	Overdose (Age)	Other (Age)	Subtotal (N)	Total (N)
1996	Male	15, 16, 16, 16	11, 11, 13, 13, 17	-	16	10 (71.4%)	14
	Female	13, 15, 17	15	-	-	4 (28.6%)	
1997	Male	12, 14, 15, 16, 16, 17, 17	13	-	17	9 (69.2%)	13
	Female	17	-	14, 16, 16	-	4 (30.8%)	
1998	Male	14, 15, 15, 16, 16	14, 17	-	16	8 (80.0%)	10
	Female	16, 16	-	-	-	2 (20.0%)	
1999	Male	15, 15, 16	15, 15, 15, 15, 16, 17, 17	-	14, 17	12 (92.3%)	13
	Female	-	15	-	-	1 (7.7%)	
2000	Male	13, 17, 17, 17, 16	14, 16	16	-	8 (72.7%)	11
	Female	14, 16	17	-	-	3 (27.3%)	
2001	Male	14, 15, 15, 15, 16, 16, 17	-	-	-	7 (77.8%)	9
	Female	15	14	-	-	2 (22.2%)	
1996-2001 Total	Male	31 (57.4%)	17 (81.0%)	1 (1.9%)	5 (9.3%)	55 (77.5%)	70
	Female	9 (56.3%)	4 (19.0%)	3 (18.8%)	0	16 (22.5%)	
	Total	40 (57.1%)	21 (30.0%)	4 (5.7%)	5 (7.1%)	70	
2002	Male	16, 16, 17	11, 12, 15, 17, 17, 17	16	13	11	12
	Female	16				1	
2003	Male	12, 13, 13, 16, 17	15		17, 17	8	10
	Female				14, 16	2	
2002-2003 Total	Male	8	7	1	3	19	22
	Female	1	0	0	2	3	
	Total	9 (40.9%)	7 (31.8%)	1 (4.5%)	5 (22.7%)	22	

Table 15.

Intentional injury	1996 (Age)	1997 (Age)	1998 (Age)	1999 (Age)	2000 (Age)	2001 (Age)	1996-2001 Total	2002 (Age)	2003 (Age)	2002-2003 Total
Criminal child abuse or neglect (convicted)										
Blunt force trauma	1y, 2y	7wks, 1, 18m, 7y ¹⁶	4y			3y	8	8m	2m, 2y, 2y	4
Chronic physical abuse		9m	1y			2m	3		3y	1
Dehydration / malnutrition	1y, 3y						2			0
Drown (tub)		8m					1			0
Drowning (pool)							0	7y		1
Hypothermia							0		4y	1
Illicit drug overdose (provided by parent)		17y					1			0
Scalding water (bath tub)	2m			2y			2	3y	2y	2
Shaken Baby / Shaken Infant Syndrome		2m	9m	3y	2m, 3y	4m	6	2m, 3m, 1y	2m, 10m, 1y	6
Smothered						2y	1			0
Other							0	10y		1
Subtotal (N)	5	8	3	2	2	4	24 (38.1%)	7	9	16 (57.1%)
Homicide / manslaughter (alleged or convicted)										
Firearm	13y, 14y, 15y, 17y, 17y, 17y	12y, 15y, 15y, 16y, 16y, 17y	15y, 15y, 15y, 17y, 17y, 17y	17y, 17y, 17y	2y, 3y, 12y, 14y, 15y, 16y, 17y, 17y, 17y	17y, 17y, 17y	33	2y, 13y, 17y, 17y	4m, 15y, 16y, 17y	8
Stabbing				5y & 8y ¹⁷			2	16y		1
Strangulation					7y & 13y ¹⁷ , 17y		3	17y		1
Unknown				3y			1		4y, 13y	2
Subtotal (N)	6	6	6	6	12	3	39 (61.9%)	6	6	12 (42.9%)
Total (N)	11	14	9	8	14	7	63	13	15	28

Ages are given in years (y), months (m) and weeks (wks).

¹⁶ Original abuse occurred at age 2.

¹⁶ Trauma occurred at age 2.

¹⁷ Siblings.

Table 16.


Parental / Caretaker Neglect	1996 (Age)	1997 (Age)	1998 (Age)	1999 (Age)	2000 (Age)	2001 (Age)	1996-2001 Total	2002 (Age)	2003 (Age)	2002-2003 Total
Failure to protect from hazard										
Dog attack	8y, 11y		1y, 8y	1y, 6y	5m, 1y, 1y	1y	10	4y		1
Drowned (tub, container, pool, river)								1y, 2y	1y, 4y, 4y	5
Residential fire		7y, 12y	10m, 2y	2y, 2y, 1y & 7y	8y		9			0
Other	7m	2y	1y	1, 2		3y	6			0
Failure to provide necessities										
Starvation / dehydration						12d	1			0
Failure to seek medical care / follow treatment										
Failure to provide medical attention					nb, 3 wks		2			0
Other	15y						1			0
Suffocated under furniture							0	1y		1
Total (N)	4	3	5	8	6	3	29	4	3	7
Inconclusive (Not enough information to determine neglect)										
Construction site accident						6y	1			0
Drowning, tub		5y					1		1y	1
Drowning, commercial pool			7y				1		4y	1
Drowning / near-drowning, pond			9y				1			0
Drowning / near-drowning, shore collapse		7y					1			0
Fall from motor vehicle		3y					1			0
Medical neglect		4y					1			0
Medical neglect / possible abuse		1y					1			0
Total (N)	0	5	2	0	0	1	8	0	2	2

Ages are given in years, months (m), weeks (wk), and newborn (nb).

ADA/AA/EOE

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